DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Critical Literature Review: A model of psychological adjustment to scarring following planned surgery; 2) Service Improvement Project: Volunteers' experiences of helping hoarders and hoarders' experiences of being helped; 3) Main Research Project: Post-traumatic growth in mothers 2 - 6 years after stillbirth and early miscarriage.

Ryninks, Kirsty

Award date:
2018

Awarding institution:
University of Bath

Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

Kirsty Emma Ryninks

Doctorate in Clinical Psychology

University of Bath
Department of Psychology

May 2018

Word Counts

Note, all word counts exclude abstracts, figures and tables

Critical Literature Review 7017

A Model of Psychological Adjustment to Scarring following Planned Surgery

Service Improvement Project 5189

Volunteers' experiences of helping hoarders and hoarders' experiences of being helped

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Abstracts

Critical Literature Review

Individuals' lives can be profoundly affected by an altered appearance (Moss, 2005) and the perception of altered physical appearance may disturb how individuals perceive and value their bodies. Evidence suggests that socially awkward and avoidant behaviour is often displayed by others in the context of individuals with a disfigured appearance (Bull & Rumsey, 2012). 4.7 million people were admitted to hospital for a surgical procedure in the UK in 2013/14 (Royal College of Surgeons, 2016). While most individuals are happy to have treatment to improve their medical conditions and/or lengthen their life, many also face the reality of altered appearance through scarring as a result of their surgery. There may be limited understanding in the medical field that what is done in surgery in the context of "fixing" could have the impact of creating another set of problems for patients. Scars rarely pose a health risk and yet patients frequently present with scar-related aesthetic, social and psychological distress (Chacon, França, Ledon, & Nouri, 2013). Although a number of models have been developed to understand the concepts of appearance and disfigurement, there is limited research which directly addresses the important 'side effect' of common medical procedures, 'surgical scarring'. This narrative review aims to synthesise the existing literature on surgical scarring and appearance within a broadly cognitive-behavioural framework to develop a better understanding of psychological adjustment to scarring following planned surgery. A number of existing models provide a useful framework to understand adjustment to scarring following burns, traumatic injury and pre-existing disfiguring conditions; however, they do not sufficiently aid understanding of adjustment to planned surgery and health professionals do not have a framework to aid targeted preparation for surgery/treatment. We therefore propose a new model of psychological adjustment to scarring following planned surgery and focus on aiding health professionals to better help their patients through the development of specific and targeted preparation and treatment in the future. The review concludes by highlighting the importance of shifting the focus in medicine from 'functioning body parts' to positive psychological adjustment and wellbeing following planned surgery.

Service Improvement Project

Objectives. The present study aimed to explore the experiences of compulsive hoarders and volunteer helpers within the context of a UK-based charity providing support to older adults with hoarding difficulties.

Design. Qualitative methods were adopted to investigate the lived experience of participants and add meaning to current understandings of compulsive hoarding.

Methods. A total of 7 volunteers and 4 clients (compulsive hoarders) were recruited and interviewed using a semi-structured interview, designed to explore experiences of providing and receiving help. Qualitative analysis of the interview data was performed using Interpretive Phenomenological Analysis.

Results. Four superordinate themes were identified: relationship between client and volunteer; 'live life again'; challenges; and supporting volunteers. The relationship was crucial in providing a trusting foundation from which clients felt able to move forward. Volunteers provided a space for clients to talk and appropriate self-disclosure helped to build a relationship. The informal and 'non-professional' status of volunteers enabled clients to take the lead and feel more in control of the therapeutic process. Volunteer flexibility and lack of time constraints contributed to clients 'making space'. The support from volunteers enabled clients to 'live life again' and created a domino effect, bringing about improvements in other areas of their lives.

Conclusions. The findings will be discussed in relation to the training of health professionals to work with people with hoarding difficulties and the implications of the findings for treatment approaches and service provision.

Practitioner Points

- Switching the focus from hoarding and associated behaviours to the client as a person and their interests may create a space for change and bring about improvements in compulsive hoarders' quality of life.
- Services may benefit from developing separate pathways for compulsive hoarders, focused on allowing volunteers and professionals time and flexibility to build the therapeutic relationship in the future.
- In light of this study's small sample size, the findings may have limited generalisability.
- Purposive sampling may have excluded clients experiencing greater shame and embarrassment.

Main Research Project

Background. The possibility of posttraumatic growth (PTG) in the aftermath of pregnancy loss has received limited attention to date. This study investigated PTG in mothers two to six years following stillbirth (SB) compared to early miscarriage (EM). It was hypothesised that mothers following SB will demonstrate more (1) PTG, (2) challenge to assumptive beliefs, and (3) disclosure than mothers following EM. The study also sought to understand how theoretically-derived variables of the Model of Growth in Grief (challenge to assumptive beliefs and disclosure) explained unique variance in PTG when key factors were controlled for.

Methods. One hundred and twenty women who had experienced a SB (N=57) or EM (N=63) two to six years ago completed validated questionnaires relating to PTG and key variables relevant to emotional adjustment post-bereavement.

Results. Participants who had experienced a SB demonstrated significantly higher levels of PTG, posttraumatic stress symptoms, perinatal grief, disclosure, challenge to assumptive beliefs and rumination than participants who had experienced an EM. In a hierarchical stepwise regression analysis, challenge to assumptive beliefs alone predicted 17.6% of the variance in PTG. Intrusive and deliberate rumination predicted an additional 5.9% of variance, with urge to talk and actual self-disclosure predicting a further 14.7%. A final model including these variables explained 46.4% of the variance in PTG.

Conclusions. Significantly higher levels of PTG were found in mothers following SB compared to in mothers following EM. Mothers experienced greater challenge to their assumptive beliefs and revealed higher levels of actual self-disclosure and greater urge to talk following their SB. These findings can partially be explained by differences in key variables from the Model of Growth in Grief.

Keywords: Posttraumatic growth, stillbirth, early miscarriage, disclosure, pregnancy loss

Critical Literature Review

A Model of Psychological Adjustment to Scarring following Planned Surgery

Kirsty Ryninks
Doctorate in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: K.E.Ryninks@bath.ac.uk

Word count: 7017

May 2018

Internal/academic supervisors: Professor Paul Salkovskis and Dr Cara Davis;
Doctoral Programme in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: P.M.Salkovskis@bath.ac.uk and C.Davis@bath.ac.uk

External/field supervisor: Dr Nell Ellison, Bristol Royal Hospital for Children
University Hospitals Bristol NHS Foundation Trust
Upper Maudlin Street, Bristol, BS2 8BJ
Email: nell.ellison@uhbristol.nhs.uk

Proposed Journal: Body Image

Please see Appendix I for instructions to authors

Outline of the Review

Individuals' lives can be profoundly affected by an altered appearance (Moss, 2005) and the perception of altered physical appearance may disturb how individuals perceive and value their bodies. Evidence suggests that socially awkward and avoidant behaviour is often displayed by others in the context of individuals with a disfigured appearance (Bull & Rumsey, 2012). 4.7 million people were admitted to hospital for a surgical procedure in the UK in 2013/14 (Royal College of Surgeons, 2016). While most individuals are happy to have treatment to improve their medical conditions and/or lengthen their life, many also face the reality of altered appearance through scarring as a result of their surgery. There may be limited understanding in the medical field that what is done in surgery in the context of "fixing" could have the impact of creating another set of problems for patients. Scars rarely pose a health risk and yet patients frequently present with scar-related aesthetic, social and psychological distress (Chacon, França, Ledon, & Nouri, 2013). Although a number of models have been developed to understand the concepts of appearance and disfigurement, there is limited research which directly addresses the important 'side effect' of common medical procedures, 'surgical scarring'.

This narrative review aims to synthesise the existing literature on surgical scarring and appearance within a broadly cognitive-behavioural framework to develop a better understanding of psychological adjustment to scarring following planned surgery. A number of existing models provide a useful framework to understand adjustment to scarring following burns, traumatic injury and pre-existing disfiguring conditions; however, they do not sufficiently aid understanding of adjustment to planned surgery and health professionals do not have a framework to aid targeted preparation for surgery/treatment. We therefore propose a new model of psychological adjustment to scarring following planned surgery and focus on aiding health professionals to better help their patients through the development of specific and targeted preparation and treatment in the future. The review concludes by highlighting the importance of shifting the focus in medicine from 'functioning body parts' to positive psychological adjustment and wellbeing following planned surgery.

Scarring

Scars are the body's natural response to injury or damage and are areas of fibrosis that occur in normal skin following injury (França, Chacon, Ledon, Savas, & Nouri, 2013). They are the imperfect end point of the normal continuum of tissue repair (Bayat, McGrouther, & Ferguson, 2003) and can be classified as normotrophic, hypertrophic and atrophic scars (Chacon et al., 2013). Whilst hypertrophic and keloid scars are both elevated

and raised, keloids grow beyond wound boundaries and are usually pink-red, firm, itchy and tender (Philipp, Scharschmidt, & Berlien, 2008). Both keloid and hypertrophic scars can result in pain but keloids cause more severe symptoms including physical discomfort and burning sensations (Lupton & Alster, 2002).

Although scarring is a natural part of the healing process, living with scars can be challenging in a social and cultural environment that places high value on physical attractiveness and unblemished appearance (Beuf, 1990). Meaning is key; scar patients can experience wide-ranging effects that can have a major influence on their function, cosmetic appearance and psychological wellbeing (Brown, McKenna, Siddhi, McGrouther, & Bayat, 2008; França et al., 2013). Whilst for many individuals the scar may represent a symbol of recovery, a badge of honour or battle scar that can be viewed with pride, for others, the scar may be a constant reminder of what they have been through and source of stigma (Williamson & Wallace, 2012). King, McFetridge-Durdle, LeBlanc, Anzarut, and Tsuyuki (2009) reported that women's cardiac scars served as a reminder that they were: 'very ill and possibly close to death; had been through a great ordeal (either the surgery itself or beyond the surgery); had a defect corrected or remain with a weakness; and needed to take care to avoid more surgery' (King et al., 2009, p. 115).

The majority of published literature on scarring has focused on burns and traumatic injuries and therefore the management of patients with burn scars has been well documented in the literature. Across all age groups, 70% of patients with burn injury are male (Rajipura, 2002) and evidence suggests that psychological and psychiatric disorders are overrepresented in individuals with burn injuries (Klinge, Chamberlain, Redden, & King, 2009). Van Loey and Van Son (2003) reported that burn scars can have long-lasting psychological and physical implications, even after seeking remedial or cosmetic treatment, and the trauma of the accident and subsequent painful treatment may in fact induce the psychopathological responses in the first place. Lawrence, Mason, Schomer, and Klein (2012) conducted a systematic review of the impact of scarring after burn injury, indicating that psychosocial variables (e.g. social comfort and perceived stigmatisation) were more highly correlated with body image than scar characteristics. Therefore, in addition to psychological vulnerabilities contributing to the occurrence of a burn injury, psychological factors are also involved in the harm and impact that a burn injury can cause. Moreover, burn severity is not always predictive of psychological adjustment (Tedstone & Tarrier, 1997) and small burns have been reported to cause strong psychological distress (Shakespeare, 1998).

Understanding Disfigurement

Living with disfigurement can have a profound effect on those affected and intuitively, greater objective severity of a disfiguring condition may be expected to cause more psychosocial distress (Brown, Moss, McGrouther, & Bayat, 2010). In other words, an individual with extensive scarring may be expected to experience greater difficulty than someone with fewer scars (Moss, 2005). Although there is evidence of this position from anecdotal accounts (Bernstein, 1982; Thomas, 1990), MacGregor (1970) noted in her clinical work that some individuals with mild disfigurement had more difficulty adjusting than individuals with more severe disfigurements. In addition, individuals with no observable disfigurement (e.g. in Body Dysmorphic Disorder) often report high levels of distress. A number of studies in a variety of appearance conditions have since reported this position, with no clear relationship between objective severity or physical extent of the disfigurement and adjustment or level of psychosocial distress (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004; Sarwer, Whitaker, & Bartlett, 2001; Thompson, Kent, & Smith, 2002).

Moss (2005) investigated subjective and objective severity of disfigurement and psychological adjustment in four hundred surgical patients with appearance altering conditions. Patients subjectively rated the severity of their disfigurement and objective ratings of severity were made by their plastic surgeons. Results revealed that poorer adjustment was related to greater subjectively perceived severity of disfigurement. However, assessment of perceived appearance severity was measured using a simple likert scale and the ratings of subjective and objective severity were completed on two separate patient groups (objective ratings by plastic surgeons for the outpatient group and subjective ratings by patients in the waiting list group). The authors of the study therefore concluded that future research should replicate the findings within the same sample and with more advanced measures of severity. Despite there being some limitations to the study, the findings provide empirical evidence to support previously anecdotal reports that objective ratings of disfigurement do not necessarily predict distress. Rumsey and Harcourt (2004) also described anecdotal observations of the linear relationship between adjustment and subjective severity of disfigurement in their review paper on body image and disfigurement.

Brown et al. (2010) later examined psychosocial distress in patients attending a specialist scar plastic surgery clinic. Skin scars were independently assessed using validated measures on two occasions, overcoming the limitations of previous research. The results demonstrated that patients with non-visible scars suffered more psychological distress than those with visible scars, as non-visible scars provide limited chances for exposure and

conditioning. In addition, patients' own subjective assessment of their scar severity influenced patients' psychosocial morbidity ($r = 0.48$, $p < 0.0001$), whilst objective scar severity ($r = 0.14$, $p = 0.11$) did not. Evidence therefore suggests that psychological distress is not related to clinician-rated scar severity or scar type but patient-perceived scar severity is related. Although some might regard this as counter-intuitive, it appears to be the patient's subjective opinion, not objective rating, that is important when considering adjustment. This fits well with a cognitive perspective.

Surgical Treatments and Scarring

Chacon et al. (2013) reported that an estimated 100 million people in developed nations each year will acquire scars following a surgical procedure. Keloids and hypertrophic scars are the most common types of scarring following surgery and although they are not medically dangerous, they are often painful and may result in significant disfigurement to the affected area (Gauglitz, Korting, Pavicic, Ruzicka, & Jeschke, 2011). Most surgical treatments have the potential to alter appearance and result in skin scarring or disfigurement (Williamson & Wallace, 2012), including head and neck cancer (facial surgery), abdominal stoma, prostate cancer, amputation, transplants, breast cancer (lumpectomy and mastectomy) and a number of life-saving cardiac treatments. Psychological adjustment and reactions to scarring following these treatments are less well understood than in burn injury and therefore a brief summary of the literature on three of the most common conditions where surgical treatments are required will be presented next.

Head and Neck Cancer

As the face is considered a psychologically important area of the body, given its visibility and the value society places on facial attractiveness, any disfigurement to the facial area can often lead to severe consequences in social situations (Tebble, Thomas, & Price, 2004; Versnel, Plomp, Passchier, Duivenvoorden, & Mathijssen, 2012). Treatment in head and neck cancer is focused on the throat, mouth, ear, nose and eye regions and results in a number of difficulties for patients, including scarring. Appearance change is expected and treatments for advanced stages of the disease dramatically alter appearance (Williamson & Wallace, 2012).

Fingeret et al. (2012) reported that 75% of patients who had surgery as part of their treatment reported feeling concerned or embarrassed by changes to their body. Whilst this percentage is significant, the authors cautioned the generalisability of their findings as participants received treatment at a comprehensive cancer centre where the cases of head and neck cancer may have been more unusual and aggressive. However, other studies

highlight the importance of subjective ratings when considering adjustment. Negative impact on self-image is also common (Gamba et al., 1992) and Piff (1998) reported that patients often grieve the loss of their previous appearance following treatment. Social isolation is a usual occurrence in head and neck cancer and some patients have reported feeling stigmatised, with difficulty making friends and securing employment following treatment (Kent, 2000).

Anxiety, depression and reduced wellbeing have been well documented in the head and neck cancer population following surgery and Semple, Sullivan, Dunwoody, and Kernohan (2004) in their review article stated that depression and anxiety were reported by 30% to 40% of patients. There is also evidence that gender is implicated in adjustment in head and neck cancer, with women reporting lower life happiness and greater depressive symptoms (Katz, Irish, Devins, Rodin, & Gullane, 2003) than men following surgery. Social support appeared to act as a buffer between greater disfigurement and wellbeing in women, not men (Katz, Irish, Devins, Rodin, & Gullane, 2003), suggesting that women with limited social support may be more at risk of poor adjustment following surgery. In addition, greater appearance dissatisfaction and concern post-surgery have been reported in women compared to men (Liu, 2008). It has been suggested that this may be attributed to the higher importance of facial attractiveness in women, as well as the head and neck area being the most individual and personal part of the body (Williamson & Wallace, 2012). However, as only 18% of the possible sample returned their questionnaires (Liu, 2008), the findings should be interpreted with caution. Other findings by Katz et al. (2003) suggest that not all patients struggle with their appearance following treatment. Moreover, healthcare professionals are often left surprised by the distress caused from minimal changes in appearance in light of what they considered a 'successful aesthetic outcome'. Psychological distress and adjustment therefore cannot be predicted from the type or objective severity of scarring and disfigurement in head and neck cancer, as it is often the individual's subjective assessment that determines psychological wellbeing.

Breast Cancer

Treatments in breast cancer have advanced in recent decades and an increasing number of women are living with an altered appearance as a result of lumpectomies (surgical removal of part of the breast) and mastectomies (surgical removal of the whole breast). At a time of adjustment to diagnosis, women are required to make prompt decisions about their treatment and evidence suggests that appearance and body image are important factors influencing women's decisions (Williamson & Wallace, 2012). Alfano and Rowland (2006) in their review article reported that women can describe mastectomy as

a psychologically painful experience, threatening their body image and sense of identity, which is not surprising given the social connotations of femininity, sexuality and motherhood associated with women's breasts (Khan et al., 2000). In a qualitative study with nineteen women, patients frequently reported difficulties with intimacy following breast cancer surgery and attempted to conceal their scars for fear of stigma or shocking others (Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010).

Older women tend to report more positive body image following surgery than younger women, suggesting that age may also be involved in appearance-related distress, with younger women more likely to experience problems (Nissen et al., 2001). Figueiredo, Cullen, Hwang, Rowland and Mandelblatt (2004) recruited a large sample of 563 women and focused on understanding the experiences of older women (aged 67 or older), a group that had been overlooked in previous studies. Women were more likely to experience distress and poorer adjustment to their altered body if they highly valued physical appearance of their breasts (Figueiredo, Cullen, Hwang, Rowland, & Mandelblatt, 2004). Although participants were interviewed at three time points, increasing understanding of changes in adjustment over the time, the authors acknowledged that the findings may have been different if a pre-surgical assessment had been conducted (as all interviews were conducted post-surgery). Body image also proved an important factor in 31% of women's decisions about their breast cancer treatment (Figueiredo, Cullen, Hwang, Rowland, & Mandelblatt, 2004). Fobair et al. (2006) found that half of the 548 young women with breast cancer in their study experienced problems with their body image some or much of the time following treatment. Fifty five percent of women reported feeling embarrassed by their body and 45% reported feeling less feminine. Although the study only focused on young women aged 50 or under, the sample included 29% of women of colour, overcoming the limitations of earlier studies with predominantly white and well-educated samples. Feelings of emptiness and grief have also been reported by women when their changed body is compared to their former self (Alfano & Rowland, 2006). Therefore, as reported in head and neck cancer, it is the subjective satisfaction with appearance that appears to determine psychological outcome following surgical treatment for breast cancer (Williamson & Wallace, 2012).

Cardiac Surgery

Whilst the psychological impact and management of scars in head and neck and breast cancer has received some attention in the literature, very little research has been reported in psychological adjustment and reactions to scarring following life-saving cardiac surgery. The most visible sign of the surgical intervention in cardiac treatment is the scar

and therefore although one would expect body image to be given attention, Masi and Brovedani (1999) reported that few findings have in fact been published. This continues to be the case today. Body image and experience of surgical scars are important factors in psychological adjustment following cardiac surgery. In a study of 201 patients with a scar from congenital heart disease surgery, 22-25% of individuals experienced negative psychological effects of their surgical scars (Crossland et al., 2005). Geyer et al. (2006) conducted standardised interviews and medical examinations with 343 patients with congenital cardiac disease and found that the outward appearance of many patients, especially the scar and any physical impairments present, were reminders that their heart had been surgically corrected (Geyer et al., 2006). Geyer et al. (2006) therefore reported that an unfavourable body image may lead individuals to perceive themselves as defective, in turn resulting in self-doubts and a sense of insecurity. Although the study's authors cautioned their findings' generalisability to patients with more severe congenital heart disease, evidence from other studies highlight the importance of subjective ratings when considering adjustment.

King et al. (2009) explored the impact of sternal scar formation in thirteen women and found that women were not well-prepared to learn to live with their scar and were left feeling less attractive. They identified a solitary process of 'coming to terms' and 'learning to live' with their scar and some women worried that others would judge them for 'not taking care of their health', possibly due to the connotations of lifestyle choices and acquired cardiac problems. Women were also negatively affected by their subjective perception of the cosmetic impact of the scar and this effect extended months and years after their surgery. However, as the interviews were conducted at one time point (1.5-3.75 years post-surgery), it is not possible to determine how perceptions of scarring changed over time. Cardiac surgery scars were also associated with lower self-esteem and body image in one hundred adult patients with Congenital Heart Disease (Kantoch et al., 2006). Forty eight percent of patients reported that they try to conceal their scar in public and more than half of patients believed that their scars permanently disfigure their bodies. Perception of chest scarring was the same regardless of when scars were acquired, although scars acquired in adulthood exerted less impact on self-esteem and self-confidence. A greater proportion of women than men felt that their scars negatively impacted their self-confidence and self-esteem (Kantoch et al., 2006). The authors noted that the impact of past events and patients' congenital heart disease on questionnaire responses in relation to the impact of their scar is unknown. However, as reported previously, it is the patient's subjective experience of the scar itself that counts.

Psychological Preparation for Scarring following Surgery

The management of scars presents a challenge for health professionals, as scarring can greatly impact quality of life, with proneness to shame, body image problems and lack of self-esteem (Bock, Schmid-Ott, Malewski, & Mrowietz, 2006; França et al., 2013). Psychological preparation for surgery may help to reduce this challenge and patient information and preparedness have long been considered key elements of enhanced recovery pathways (Grocott, Martin, & Mythen, 2012). Whilst there are British Psychological Society (BPS) guidelines around preparation for undergoing medical procedures in children (Gaskell, 2010), there is no official guidance regarding psychological preparation for the post-procedural consequences of interventions in children or adults.

There continues to be a lack of published research addressing the important question of psychological preparation for surgery and studies continue to report poor psychological outcomes in patients following surgical scarring. King et al. (2009) in their qualitative study reported that patients were not ready for, or did not understand what was going to happen to their body following cardiac surgery. Evidence of poor psychological outcomes from a number of other studies led Papaspyros, Patel, Polyzois, Javagula, and Jeffrey (2011) to conclude that the potential impact of scar formation should be discussed with patients during consultation for surgery in their review of scar formation and impact on patient quality of life.

Patient information has traditionally been delivered in surgical and anaesthetic pre-assessment clinics, although there is increasing evidence for more sophisticated psychological preparation for surgery. Hood (2010) developed a body image toolkit for patients who experience a change to their appearance through their illness and cancer treatment. The toolkit was part of a project to improve supportive care and included a cognitive-behavioural based workbook for cancer patients and e-learning programme for clinicians. A number of studies have also described transplant preparation programmes and reported positive psychological outcomes in patients and their extended network. Davis, Ryninks, Cliss, and Dolby (2013) evaluated the renal transplant preparation programme (RTPP) offered at Bristol Royal Hospital for Children and found that 96% of parents/carers and 100% of children and young people felt that they were given all the information they needed about their transplant. Talking to different members of the team over a number of appointments and settings, as well as building relationships with various professionals offering a person-centred approach, helped patients and their families to prepare for the transplant and the outcomes of their surgery (Davis et al., 2013).

Rolving et al. (2016) used pre-operative cognitive behavioural education to prepare lumbar spinal fusion patients and Grocott, Plumb, Edwards, Fecher-Jones, and Levett (2017) described the use of classroom-based surgery schools to manage patient expectations in relation to the in-hospital surgical journey and improve psychological preparation for surgery. Williamson and Wallace (2012) stated that 'health professionals are central to the success of any attempt to help patients manage their treatment-related appearance concerns' (Williamson & Wallace, 2012, p. 431). It is therefore vital that health professionals provide opportunities for patients to raise and openly discuss their concerns about appearance, as well as to be aware of the potential risk factors for poor psychological adjustment to scarring following planned surgery. However, the contribution that health professionals can make to improve patient preparation for surgery is limited by the time available in the care pathway of some specialties between meeting the patient for the first time and the date of surgery (Grocott et al., 2017). Re-designing the pathways to surgery may therefore open opportunities in the future to improve patient care and ultimately improve psychological adjustment to scarring following planned surgery.

Models of Adjustment, Disfigurement and Appearance-Related Disorders

Over the last forty years, a number of models, theories and frameworks have been developed to understand the psychosocial impact of disfigurement and appearance, as well as the maintenance of a number of appearance-related disorders. Rumsey and Harcourt (2004) explored the psychosocial implications of living with a visible difference and identified five models that have been used to explain people's experiences of disfigurement: Dropkin (1989); Heason (2003); Newell (2000); Kent (2000) and White (2000). However, Rumsey and Harcourt (2004) concluded that the success and utility of the models was limited and required further refinement and testing. Thompson (2012) argued that one model or theory is unlikely to account for the diversity of human experience, or the breadth of activity across body image, disfigurement, attractiveness and identity in appearance-related research. Thompson (2012) highlighted the need for an inclusive and integrative framework to understand disfigurement and this is a view that has been echoed by others (Cash & Pruzinsky, 1990; Grogan, 2016; Newell, 2000; Price, 1990, 1999; Rumsey & Harcourt, 2012). We review the most applicable models next, with a view to informing a theoretical framework for surgical scarring following planned surgery and its consequences.

The ARC Framework of Adjustment to Visible Difference (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014)

The Appearance Research Collaboration (ARC) developed a framework to guide their research programme and facilitate the identification of factors contributing to resilience or with the potential to be amenable to change (Clarke et al., 2014). The initial working framework was refined following the analysis and synthesis of the results and the final framework (The ARC Framework of Adjustment to Visible Difference), incorporating the results of the ARC programme can be found in figure 1.1.

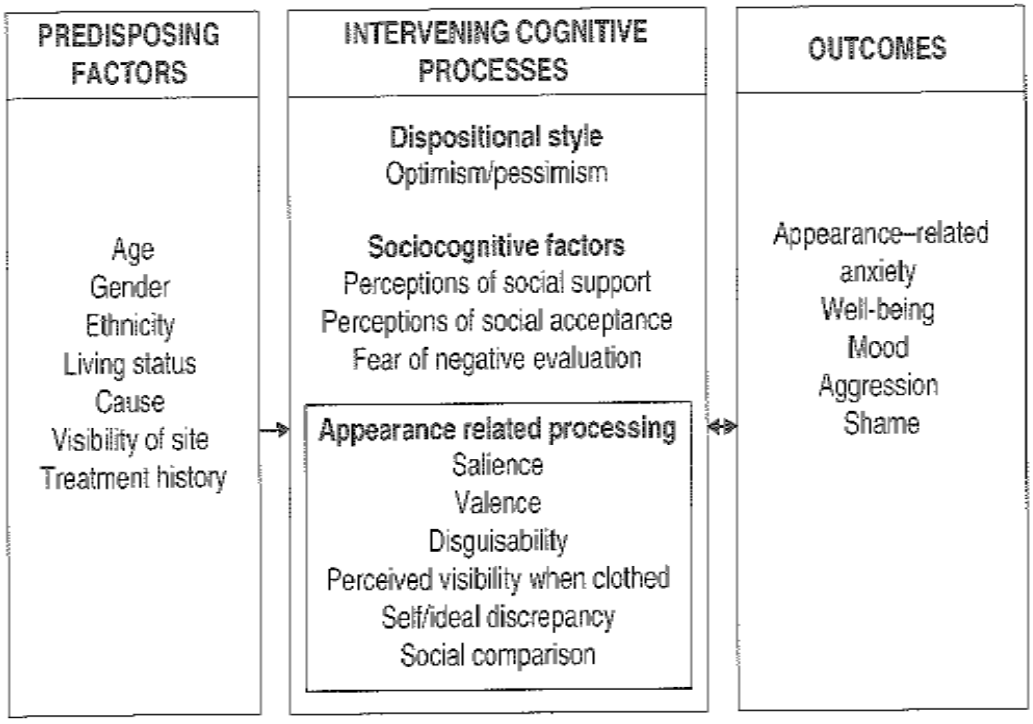

Figure 1.1. The ARC Framework of Adjustment to Visible Difference

[Reproduced from Clarke et al. (2014) CBT for appearance anxiety: psychosocial interventions for anxiety due to visible difference, p.270. © 2014 John Wiley & Sons, Ltd, with kind permission]

The ARC Framework of Adjustment to Visible Difference incorporates significant aspects of previous models (Cash, 2002; Gilbert, 2002; Kent & Thompson, 2002) with the main findings and trends in appearance research. Within the framework, the process of adjustment to visible difference is made up of three facets: predisposing factors, intervening cognitive processing and outcomes (Clarke et al., 2014). Firstly, predisposing factors are implicated in the development of core beliefs about the self, world and others and include demographic factors such as age and gender, as well as the cause, treatment history and visibility of the site. Secondly, a number of intervening cognitive processes are understood

to process appearance-related information and maintain the overall appearance schema. These include the dispositional style (optimism/pessimism) of the individual, as well as a number of socio-cognitive factors (perceptions of social support/social acceptance, fear of negative evaluations) and appearance-specific cognitions. The final facet is the outcomes of having a visible difference, including appearance-related anxiety, wellbeing, mood, aggression and shame. Further explanation of the framework and findings of the ARC can be found in Clarke et al. (2014).

A Cognitive Behavioural Model of Body Dysmorphic Disorder (BDD)

Alongside the development of models, theories and frameworks to understand the psychosocial impact of disfigurement and appearance more broadly, a number of models have been developed to understand the development and maintenance of specific appearance-related conditions and disorders such as Body Dysmorphic Disorder (BDD). BDD can be understood as 'a preoccupation with an imagined defect in one's appearance or, in the case of a slight anomaly, the person's concern is markedly excessive' (Veale, 2004, p. 113). The person must also be significantly distressed or handicapped in his or her occupational and social functioning (American Psychiatric Association, 2013). Over the last twenty years, three cognitive behavioural models have been proposed by Wilhelm (Wilhelm, Buhlmann, Hayward, Greenberg, & Dimaite, 2010; Wilhelm, Phillips, & Steketee, 2013), Veale (Veale, 2001; Veale, 2004; Veale et al., 1996) and Neziroglu (Neziroglu, Roberts, & Yaryura-Tobias, 2004) to understand the maintenance of BDD. The cognitive behavioural model of BDD (Veale, 2001; Veale, 2004; Veale et al., 1996) has strong empirical evidence and treatment derived from it has now been tested in two randomised controlled trials (Veale, 2004; Veale et al., 2014).

The model of BDD (Veale, 2004) begins with the trigger of an external representation of an individual's appearance (e.g. reflection in a mirror or photograph from when they were younger) activating a distorted mental image (figure 1.2). The process of selective and self-focused attention causes the individual to focus on specific aspects of the external representation and leads to heightened awareness of the image and an exaggeration of certain features within it. The individual uses this distorted mental image to construct how they look to others. Assumptions and values relating to appearance and its importance are activated and result in negative appraisal of appearance and processing of self as an aesthetic object. The cognitive behavioural model of BDD predicts that negative appraisals and constant appearance comparisons (either with an ideal internal image or with others) will have a negative feedback loop and increase self-focused attention on the image. It is likely that attention will also interfere with the individual's ability to process other external

information. Moreover, increases in emotional arousal tend to increase the frequency or severity of negative appraisal of one's body image and further increase self-focused attention. While safety seeking behaviours are often employed to decrease distress or uncertainty, they are counter-productive and increase self-consciousness, preoccupation and negative appraisal (Veale, 2004).

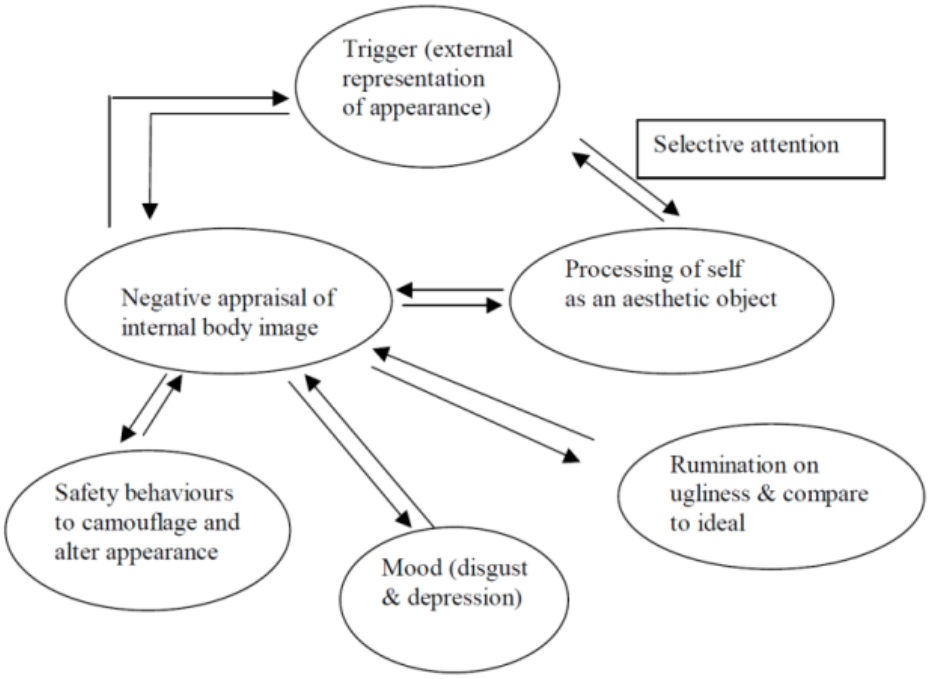

Figure 1.2. The cognitive behavioural model of BDD

[Reproduced from Veale (2004) Advances in a cognitive behavioural model of body dysmorphic disorder, with kind permission]

A number of studies have further investigated specific aspects of the BDD model, as outlined in Baldock and Veale (2017), including: selective attention and heightened awareness (Anson, Veale, & de Silva, 2012; Clerkin & Teachman, 2008; Kollei & Martin, 2014); distorted mental image (Osman, Cooper, Hackmann, & Veale, 2004; Willson, Veale, & Freeston, 2016); mirror gazing (Baldock, Anson, & Veale, 2012; Windheim, Veale, & Anson, 2011); and self as aesthetic object (Lambrou, Veale, & Wilson, 2011, 2012; Veale, Kinderman, Riley, & Lambrou, 2003).

A New Understanding of Psychological Adjustment to Scarring following Planned Surgery

Although a number of models, theories and frameworks have been developed to understand the psychosocial impact of disfigurement and the maintenance of a number of appearance-related disorders, they have largely focused on when the disfigurement is already present and do not necessarily aid understanding of adjustment to planned surgery. Notably, the circumstance by which a scar is acquired and how the acquisition is managed are also important and will play a role in an individual's adjustment. Within the field of surgical scarring, it is the treatment that causes the scarring in the first place. It may therefore be helpful to intervene prior to surgery to prevent some of the difficulties described earlier in this review. Rather than propose a completely separate model to understand disfigurement, our new model (figure 1.3) builds on those previously described in the literature to better understand psychological adjustment to scarring following planned surgery. The model draws on previous research to focus on areas where health professionals might better support their patients by providing specific and targeted preparation and treatment in future. It promotes early preparation and intervention prior to surgery, with the aim of improving adjustment and psychological outcomes in the long-term, and helps identify promising research areas.

A Model of Psychological Adjustment to Scarring following Planned Surgery

The model presented here is composed of two main components: developmental and triggering aspects which contribute to meaning, and maintaining factors which arise from and can in turn influence those meanings. These are predominantly drawn from the literature reviewed above within a cognitive-behavioural theoretical framework.

Before the Operation/Surgery

Taking developmental and triggering factors first. A number of pre-existing factors (as outlined previously by Clarke et al. (2014)) may influence an individual's anticipated experience of their surgery and their reactions post-operatively. Katz et al. (2003) reported that women experienced lower life happiness and greater depressive symptoms following treatment for head and neck cancer than men, as well as more appearance dissatisfaction and concern (Khafif et al., 2007; Liu, 2008). Nissen et al. (2001) found older women tend to report more positive body image following breast cancer surgery than younger women and Hood (2010) reported appearance concerns were less important in older women. Gender and age may therefore play a role in adjustment, although evidence from other studies suggests that the role of these factors may not be so clear cut.

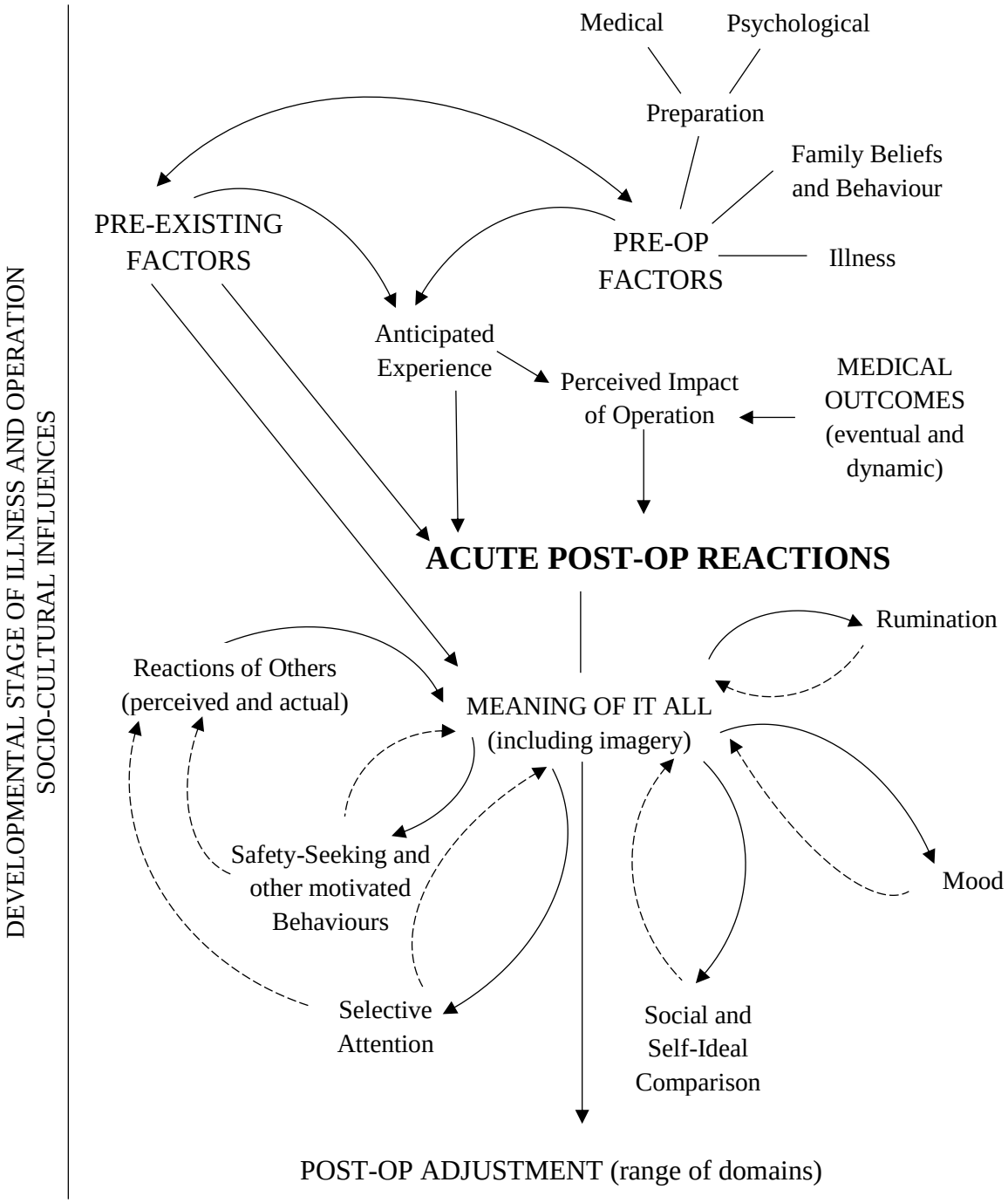

Figure 1.3. A Model of Psychological Adjustment to Scarring following Planned Surgery.

This model is meant to summarise the full range of adjustment to scarring following planned surgery, from good to problematic. The upper part of the figure shows influences which have been noted to mediate or moderate the meaning attached to scarring; the lower section indicates processes which, if the meaning is particularly negative, may maintain psychological problems occurring as a consequence of scarring.

Societal and cultural influences (including the media) are also important when considering adjustment to scarring. Beliefs that society places a high value on attractiveness (Tebble et al., 2004; Versnel et al., 2012), as well as social connotations of femininity, sexuality and motherhood of the chest region (Figueiredo et al., 2004; Khan et al., 2000) may feed into an individual's anticipated experience and resulting perceived impact of surgical scarring. Sociocultural influences therefore need to be considered as part of preparing individuals for surgery (whilst simultaneously bearing in mind the ultimate need to change attitudes about appearance at a societal level, rather than simply supporting individuals in this regard). The developmental stage within which the illness is acquired and the developmental stage in which the operation occurred or scar is acquired are also important and will affect an individual's adjustment to scarring following surgery. Kantoch et al. (2006) reported that scars acquired in adulthood exerted less impact on self-esteem and self-confidence than those acquired in childhood or adolescence.

Siegel (2010) reported that the foundation of our sense of self is built upon the intimate exchanges we have as babies. Where the exchanges have been positive, individuals develop secure attachments. In contrast, where the exchanges have been less positive, individuals may develop a variety of insecure attachment styles. A positive sense of self and self-image are developed through secure attachments with parents and caregivers (Sroufe, 1995, 1997) and these individuals score highly on resilience, adaptability and self-esteem. Factors such as bullying in childhood can contribute to an individual's increased risk of developing adverse physical health, emotional and psychological outcomes in childhood (Reijntjes, Kamphuis, Prinzie, & Telch, 2010), as well as a poor sense of self and increased risk of poor health, wealth and social-relationship outcomes in adulthood (Wolke, Copeland, Angold, & Costello, 2013). Individuals with a less positive sense of self and self-image may therefore be more likely to have poorer adjustment to scarring following surgery.

In addition, temperament (broadly defined by Derryberry and Rothbart (1988) as an emotional and behavioural style appearing in early life that is consistent across time) and more specifically negative affectivity (a tendency towards discomfort, fear, anger, sadness, and low soothability) have been shown to be linked to anxiety and depression, as well as maladaptive coping styles (Miller et al., 2009). Since temperament is less malleable than coping style, it is likely that certain temperamental traits may prevent some individuals from using effective coping strategies following surgery and consequently have poorer outcomes. As with previous models of adjustment and disfigurement, pre-existing factors influence the meaning that the individual makes of their changed appearance (surgical scar). Individuals with a more positive sense of self and self-image and who attach less meaning to their

appearance and body image may adjust better following surgical scarring. Pre-operative factors also feed into an individual's anticipated experience, with evidence suggesting that a lack of preparation may result in individuals being poorly-prepared to live with their scar (King et al., 2009). Psychological and medical preparation (e.g. anticipated medical outcomes and patient journey, length of recovery) are therefore critical to individuals being prepared for all eventualities of the surgery.

Family beliefs and behaviour are also involved in adjustment, as particular parenting styles and family dynamics will affect how the family and individual prepare for their operation and experience illness. It is therefore important to ensure that the wider family is also prepared and supported, rather than only focusing attention on the individual undergoing the surgery. Whilst some families may encourage discussions about their feelings around the operation and illness and address any that may be considered problematic, others may avoid discussions completely or only talk at the last minute. Evidence suggests that sharing and talking about one's thoughts, emotions and experiences in relation to health results in more positive adjustment (Mallinger, Griggs, & Shields, 2006). Manne, Pape, Taylor, and Dougherty (1999) found that patients undergoing active treatment for breast cancer who perceived that their spouses did not want to talk about cancer-related issues experienced greater psychological distress. Finally, pre-operative and pre-existing factors influence each other in a bidirectional way, as attachment style, temperament and other demographic factors will affect how the individual and their family prepare for the operation.

After the Operation/Surgery

The anticipated experience is important when considering psychological adjustment to scarring as it influences the individual's resulting perceived impact of the operation and post-op reaction and meaning. Although surgical scarring is the result of an operation that broadly aims to improve an individual's health and/or functioning, the operation and scar may not occur as planned. Whilst the eventual medical outcomes of surgery contribute to the meaning that the individual makes of their changed appearance, a number of dynamic factors (short term/immediate medical outcomes) also play a role. For example, the circumstances around the operation itself are important as they may mean a change in the anticipated pathway of treatment. Complications and a long stay in intensive care may take individuals by surprise and make them question beliefs about mortality and their patient journey. Anecdotal observations suggest many individuals focus upon their desired positive outcome (improved health and/or functioning), without consideration of the process (surgery) they must go through in order to obtain their positive outcome in the first place.

Although a focus on outcome may be an effective coping strategy for some, for individuals where there are complications (the scar is worse than anticipated or surgery does not produce the desired or anticipated positive outcome) psychological adjustment to surgical scarring may be poor. Individuals' beliefs about the level of pain they will experience, their likelihood of dying in surgery and loss of control all contribute to their anticipated experience, with factors such as increased pain negatively influencing the meaning they make of their surgery. Therefore, rather than the scar representing a symbol of their positive outcome, it may now represent disappointment and anger at an unsuccessful outcome or complications they had to endure.

In addition, the reactions of others (both perceived and actual) impact upon the meaning that an individual makes of their surgery and changed appearance. Partridge (1990) highlighted the varied reactions of family and friends to facial disfigurements, with some committed to supporting their loved one and others avoiding or rejecting the individual who had been disfigured. Some patients with head and neck cancer have reported feeling stigmatised, with difficulty making friends and securing employment following treatment (Kent, 2000). Piot-Ziegler et al. (2010) found women frequently reported difficulties with intimacy following surgery and attempted to conceal their scars for fear of stigma or shocking others. Regardless of the cause of disfigurement (acquired versus congenital), the most frequently reported difficulties relate to encounters with strangers, meeting new people and making new friends (Robinson, 1997). It is therefore important to consider the reactions of others as part of preparation for surgery, including the possibility of a self-fulfilling prophecy where individuals may anticipate negative reactions and therefore behave in a shy or defensive manner, in turn inviting negativity from others.

Crucially, the meaning that an individual attaches to the process they have been through and its outcomes results in a number of behavioural changes and processes that have been well described previously and determine post-operative adjustment, including social and self-ideal comparison, safety-seeking and other motivated behaviours (e.g. attempts to conceal scars, Piot-Ziegler et al. (2010)), rumination, selective attention and mood (e.g. anxiety and depression, Semple et al. (2004)). Where the meaning is particularly negative, this will be maintained to the extent that these responses hold it in place or increase it in terms of negativity, in the way seen in persistent health anxiety (Salkovskis & Warwick, 1986) and BDD (Veale, 2004).

Summary

Over the last fifty years, a number of models, theories and frameworks have been developed to understand the psychosocial impact of disfigurement and the maintenance of a number of appearance-related disorders. They have largely focused on understanding adjustment when the disfigurement is already present. However, the circumstance by which a scar is acquired and how the acquisition is managed are also important and will play a role in an individual's adjustment. This review highlights the importance of shifting the focus in medicine from 'functioning body parts' to positive psychological adjustment and wellbeing following surgery. The management of scars presents a challenge for health professionals, as scarring can greatly impact upon quality of life, with proneness to shame, body image problems and lack of self-esteem (Bock et al., 2006; França et al., 2013). Within the field of surgical scarring, it is the treatment that causes the scarring in the first place. Psychological preparation for surgery may help to reduce this challenge and patient information and preparedness have long been considered key elements of enhanced recovery pathways (Grocott et al., 2012).

Psychologists working in health settings have been asking for a model to formulate and improve psychological outcomes in their patients. Rather than propose a completely separate model to understand disfigurement, our model builds on those previously described in the literature (Clarke et al., 2014; Veale, 2004) to better understand psychological adjustment to scarring following planned surgery. The model draws on previous research to focus on areas where health professionals might better support their patients by providing specific and targeted preparation (preventatively focused) and treatment where scar related distress becomes persistent. It promotes early preparation and intervention prior to surgery, with the aim of preventing some of the difficulties described earlier in this review. This should have the benefit of improving adjustment to surgical scarring and psychological outcomes in the long-term, and helps to identify promising areas of research. Moreover, elements of our model may be useful in understanding adjustment in other appearance-related conditions where context and preparation might be key.

Clinical Implications

The literature in this review highlights that it is the patient's subjective opinion of their scar that counts when considering adjustment. Health professionals may objectively see the scar in a 'positive' light and make assumptions about how the patient will respond; however, it is important for health professionals to consider the patient's perception of their scar, how they may respond to it (e.g. conceal) and how it may be perceived by others in

order to tailor their approach to patients accordingly. Evidence from the BDD literature highlights the challenges of helping patients to talk about their appearance concerns (Marques, Weingarden, LeBlanc, & Wilhelm, 2011). Health professionals therefore need to feel confident in raising these issues with their patients and may benefit from training in how to ask the right questions, and not to take answers at face value. It is also vital that health professionals are aware of the potential risk factors for poor psychological adjustment to scarring following planned surgery, and that they provide opportunities for patients to raise and openly discuss their concerns about appearance and medical outcomes. Our model provides a framework for multidisciplinary teams to do this. Helping patients to understand and process the stories of their scars (e.g. successes and complications) may also help them to create meaning (e.g. reminder of strength or bravery vs. sign of weakness). Health professionals can therefore model positive story-telling to patients by talking through the more difficult aspects of the surgery and helping patients and their families to re-frame and feel more able to tell their stories themselves (see Davis et al., in preparation, for further discussion). Where concerns about scarring remain, health professionals may find it useful to refer patients for psychological support or signpost to appearance concern websites and charities (e.g. Changing Faces and YP Face IT). Care pathways may need to be redesigned to create space for these conversations to occur and new pathways could be developed for those where surgical procedures are expected to result in scarring. Such a care pathway could include the development of new tools for surgical preparation and a post-surgical stepped-care approach to psychological reactions. Self-help and psychoeducation material (drawing on the understanding summarised in this paper) can be provided as part of routine care. More focused self-help materials can be used post-operatively for individuals experiencing difficulties in adjustment and where problems persist and substantially impact on quality of life, treatment drawing on the model defined here could be offered. However, making changes to existing care pathways is contingent upon service managers and commissioners seeing the value in working in this way. It is hoped that psychologists working in health settings can use this model to provide teaching and training to their multidisciplinary colleagues to increase confidence in holding these conversations with patients and their families in the future.

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Service Improvement Project

Volunteers' experiences of helping hoarders and hoarders' experiences of being helped

Kirsty Ryninks
Doctorate in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: K.E.Ryninks@bath.ac.uk

Word count: 5189

May 2018

Internal/academic supervisors: Dr James Gregory and Dr Vuokko Wallace;
Doctoral Programme in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: J.D.Gregory@bath.ac.uk and V.Wallace@bath.ac.uk

Proposed Journal: British Journal of Clinical Psychology

Please see Appendix IV for instructions to authors

Introduction

Hoarding disorder is characterised "by persistent difficulty discarding or parting with possessions" and "causes clinically significant distress or impairment in social, occupational and other important areas of functioning" (American Psychiatric Association, 2013). This difficulty results in the accumulation of possessions and causes living areas to become cluttered and their proposed use significantly compromised. Hoarding has been reported to result in economic, familial and social burden (Frost, Steketee, & Williams, 2000), with the severely restricted use of living areas, along with feelings of shame and embarrassment often creating a barrier to others accessing the home (Coles, Frost, Heimberg, & Steketee, 2003).

Studies have repeatedly reported evidence that symptoms of hoarding emerge in mid-to-late childhood (Frost & Gross, 1993; Grisham, Frost, Steketee, Kim, & Hood, 2006), with symptom severity increasing with every decade of life (Ayers, Saxena, Golshan, & Wetherell, 2010). Eckfield and Wallhagen (2013) reported significantly higher rates of hoarding in adults over 55 years old and according to service providers, hoarding behaviour posed a serious physical threat in 81% of their elderly clients (Kim, Steketee & Frost, 2001). Hoarding has been found to increase the risk of falls, fire hazards, food contamination, social isolation and medication mismanagement (Ayers et al., 2010); hoarding can therefore pose serious consequences for older adults. Although there is high comorbidity with hoarding and other mental health conditions (Mataix-Cols et al., 2010), Pertusa et al. (2010) reported that there is an unwillingness amongst hoarders to acknowledge their problem as a mental health difficulty and to access help from services. Agencies who are responsible for supporting adults in later life consequently provide a key route through which to identify and work with hoarding difficulties (Frost et al., 2000).

A diverse range of professionals are involved in working with hoarders, including social services, medical, fire, environmental and mental health professionals (Slatter, 2007). Social service agencies have tended to employ a fragmented treatment approach, with occasional interventions often resulting in relapse (Damecour & Charron, 1998). The Chartered Institute of Environmental Health (2009) describes involvement of environmental health in cases related to hoarding when complaints have been made by neighbours or there are concerns regarding risk to physical health. When regulations regarding sanitation, antisocial behaviour or health are breached, clearance is mandatory, but evidence suggests that clearance interventions have poor long-term prognosis due to the absence of insight/behaviour change (Chartered Institute of Environmental Health, 2009).

Studies have repeatedly reported modest successes and high rates of drop out when working with this client group (Stekete & Frost, 2007; Turner, Steketee, & Nauth, 2010). Ayers, Wetherell, Golshan, and Saxena (2011) recruited twelve adults aged over 65 years to examine the impact of a manualised cognitive-behavioural therapy (CBT) protocol for compulsive hoarding. Although the findings revealed statistically significant changes to depression scores and hoarding severity, only three adults were identified as treatment responders and at follow-up their progress had not been maintained. Ayers, Bratiotis, Saxena, and Wetherell (2012) used a qualitative approach to explore therapist and patient perspectives of their specialised CBT protocol. The therapeutic relationship, exposure exercises and home visits were reported by patients to be most helpful whereas cognitive-behavioural formulations and techniques were not helpful. Therapists considered session and homework compliance to be critical to treatment outcomes.

Compulsive hoarding is widely thought of as a difficult problem to help with (Tolin, Frost, & Steketee, 2012) and evidence suggests that supporting elderly clients who hoard represents a significant challenge to services (Turner et al., 2010). Most studies to date have focused on understanding the experiences of professionals and public sector workers with people who hoard. Negative and judgmental attitudes, as well as burnout, frustration and helplessness have also been reported (Frost, Tolin, & Maltby, 2010). More recently, Holden, Kellett, Davies, and Scott (2016) explored the experience of professionals (e.g. social care, mental health, environmental health, fire service) working with clients that hoard. They found that professionals experience and approach their work in discrete and dissimilar ways, identifying three distinct clusters of professionals: therapeutic and client-focused, shocked and frustrated, and pragmatic and task focused.

Given the outcome data and reported difficulty of working with hoarders, it is important to understand the factors that act as barriers and facilitators in supporting people with compulsive hoarding. Service constraints and increasingly pressurised financial budgets are causing services to seek new ways to support their clients. Evidence suggests that support from non-professionals may be helpful in enhancing clients' physical and mental wellbeing (Taft et al., 2011; Uhm et al., 2016). The present study aimed to explore the experiences of compulsive hoarders and volunteer helpers within the context of a UK-based charity providing support to older adults with hoarding difficulties.

Method

Participants and Recruitment

Participants were recruited through a UK-based charity that provides advice and assistance to enable older and disabled people to continue living independently. The charity's 'Making Space' project developed with the aim of volunteers providing practical and emotional support to adults with hoarding tendencies. A purposive sample of eleven participants from the Making Space project participated in the study. Four clients (two males and two females), who self-identified as having a problem accumulating numerous possessions, were interviewed in their own homes. Seven volunteers (two males and five females) were interviewed at the charity's office base. Ethical approval was granted by the University of Bath Psychology Ethics Committee (16-148).

All volunteers working for the project were sent an information sheet inviting them to participate in an interview about their experience of working with hoarders through the hoarding project. Clients of the project were approached by the volunteer currently working with them or sent a letter inviting them to participate in an interview by post. All participants consented to take part in the interview and completed a demographic questionnaire.

To establish clutter severity, volunteers were also asked to complete the Clutter Image Rating Scale (CIRS; Frost, Steketee, Tolin, & Renaud, 2008), a self-report measure of level of clutter in the home. The CIRS comprises nine photos of increasing clutter representing a kitchen, a living room and a bedroom. Each room is scored (1-9) and a composite score is calculated. A score of four and above is indicative of problematic clutter. To assess the presence and severity of acquisition, discarding and clutter behaviours, all clients completed the Savings Inventory Revised (SI-R; Frost, Steketee, & Kyrios, 2001), a self-report measure of hoarding severity. The SI-R is a 23 item questionnaire with a total available score of 92, a score of 40 or above is indicative of clinically severe hoarding difficulties.

Design

Qualitative methods were adopted to explore participants' experiences in depth and identify new concepts (Pope & Mays, 1995). Interpretive Phenomenological Analysis (IPA; Smith & Osborn, 2008; Smith, 1996) was considered a suitable approach for this study as it captures an individual's personal experiences and recognises our experiences influence how we view the world around us (Yardley, 2000). IPA is concerned with an individual's subjective report, rather than formulating an objective account. It is a dynamic process

whereby the researcher adopts an active role to take an insider's perspective and use their own conceptions to interpret information (Smith & Osborn, 2008; Smith, 1996).

Data collection

All interviews were audio recorded with participants' consent and lasted between 40 to 60 minutes. The interviews were transcribed verbatim and anonymised (V1-7; C1-4) to ensure confidentiality and privacy of participants. The interviews were semi-structured and aimed to elicit information about volunteers' experiences of providing and clients' experiences of receiving help. An interview schedule with open-ended questions was developed prior to the interviews using relevant research literature and was used to facilitate the participants' ability to tell their story in their own words, a central premise of IPA. Participants were encouraged to speak freely and openly about their experience and therefore played a central role in the interview.

Analysis

The data from the qualitative interviews was manually analysed using IPA and classified and coded by key concepts, themes and emerging categories (Smith & Osborn, 2008). The background and stance of the research team was cognitive-behavioural, and interpretations of the interview data were taken from this position. Each interview transcript was repeatedly read and listened to. Initial notes and possible codes, summarising the experience described by participants, were noted in the margin. The transcripts were re-read and theme titles that emerged were noted. To maintain the phenomenological nature of IPA, key phrases and words from the interview data were used to describe themes. The same process was followed to analyse each interview and new theme clusters were checked against the original transcripts as they emerged to ensure foundation in participants' narratives and shared understanding. Themes were updated by shared meaning as the analysis progressed and a number of superordinate themes were identified.

Themes with low frequency across participants or weak evidential base were discarded. One volunteer talked about her difficulty maintaining boundaries without insulting her client or damaging the therapeutic relationship. She described how her client was very generous and would often make attempts to give her gifts. However, this contradicted the charity's professional boundaries as volunteers are unable to accept gifts. Another volunteer described feeling disappointed and hopeless following an unsatisfactory ending with her client when their work together ended abruptly. Although these themes had low frequency across participants and were therefore discarded, they provide an insight into the impact of the work on volunteers.

A number of validation methods and credibility checks were adopted. Regular meetings were held by the research team to ensure transparency of process and collectively move from data collection to final interpretations. The research team individually reviewed a sample of the transcripts which further helped the primary researcher to reflect on the development of themes. In keeping with the principles of IPA, the analysis presented is the researchers' interpretation of the data and other interpretations and perspectives are entirely possible.

Results

Sample Characteristics

All participants identified as White UK. The seven volunteers' ages ranged from 32-84 years and the four clients' ages ranged from 63-88 years. All clients identified that they had a problem accumulating and discarding numerous possessions and had never sought professional help for their difficulties. Volunteers had worked in the project for an average of eleven months (ranging from 4-24 months) and had worked with an average of two clients each (ranging from 1-4). Only one volunteer had previous experience of working with hoarders, describing their experience as "limited", and all volunteers had completed a half-day hoarding training as part of their project induction. Additional sample characteristics are provided in Table 2.1.

Table 2.1. *Sample Characteristics of clients and volunteers (N = 11)*

	Volunteers	**Clients**
	Mean (SD) or N (%)	Mean (SD) or N (%)
Age (years)	52.6 (21.4)	75.8 (12.6)
Gender		
Male	2 (28.6 %)	2 (50.0 %)
Female	5 (71.4 %)	2 (50.0 %)
Employment Status		
Retired	4 (57.1 %)	4 (100.0 %)
Full-time	2 (28.6 %)	-
Homemaker	1 (14.3 %)	-
Marital Status		
Married	-	2 (50.0 %)
Divorced	-	1 (25.0 %)
Widowed	-	1 (25.0 %)
Education		
GCSE or equivalent	-	1 (25.0 %)
A-Level or equivalent	2 (28.6 %)	-
Bachelor's degree	3 (42.9 %)	-
Master's degree	2 (28.6 %)	2 (50.0 %)
Other	-	1 (25.0 %)

Ratings on the CIRS (Frost et al., 2008) confirmed that clients who volunteers had worked with and referred to were compulsive hoarders. A score of four or more on the CIRS was reported by volunteers across the three room areas of kitchen, living room and bedroom (ranging from 4-9). Three of the four clients interviewed scored in the clinically significant range on the SI-R (Frost et al., 2001) at the time of interview; however, it is noted that clients reported their scores would have been higher at the start of their contact with volunteers.

Qualitative Analysis

Four superordinate themes were developed: relationship between client and volunteer; 'live life again'; challenges; and supporting volunteers (see Table 2.2). All eleven participants provided example quotations of themes, ensuring adequate coverage across participants. Each theme will be discussed in turn using direct quotations to illustrate them.

Table 2.2. *Superordinate and Subordinate themes*

SUPERORDINATE THEME	SUBORDINATE THEME
Relationship between client and volunteer	Space to talk Non-professional status Client led
Live life again	Making space Company and quality of life Domino effect
Challenges	Shame and embarrassment Discarding possessions Uncertainty
Supporting volunteers	Training needs Peer support

Relationship between client and volunteer

Volunteers described that "*a lot of the early visits were in effect building up a relationship"* (V1), as well as a consensus that helping the client "*wouldn't happen if the relationship wasn't there"* (V7). Clients and volunteers both highlighted the importance of there being space to talk, where clients had someone to talk to and felt heard:

We spent a lot of time just, talking really, not necessarily about her belongings, but just talking in general. And, I think that, that helped her...I just listened…we had a bit of a laugh together. (V5)

Having someone to talk to certainly makes you feel an awful lot better about going through everything and facing one's demons or one's embarrassment. (C1)

We sit and chat…I find (volunteer) coming to chat just as important, just as helpful as the work (volunteer) does, because I can talk…we get on well, it's very easy, I can be myself with (volunteer). (C2)

Shared interests or experiences, as well as appropriate self-disclosure and an open and personable style from volunteers helped to build a relationship with clients:

Having that relationship and similar life experiences, we've been able to engage with each other…I do think that me being myself helps a lot. (V7)

Our interests are very similar. I love doing crafts as well so when she is talking about making things it is something that we can share, and I think all those things are important to her. (V2)

Volunteers and clients emphasised the importance of their informal and 'non-professional' status in their ability to build a relationship and trust with clients:

I think being volunteers…I think they kind of appreciate that we're there because we want to be, not that it's our job…it's that kind of approach we take where it is really kind of informal, it's not official, there's not a huge gap between us and them so that helps with the trust. (V7)

There's a separation between us and the local authority, or health professionals, mental health professionals, because they sometimes see those people as the boss or the people who are putting pressure on, the people in charge. They see us as more of a friendly face. (V3)

I would say I trust (the charity). Big word, you know, trust, you can't apply it to many things. (C4)

The ability of volunteers to be flexible and take their time was also identified as an important part of the relationship that developed:

I think the fact that we use volunteers. We're not on a time schedule…I think that is the joy of volunteers! We have the time or we can make the time whereas somebody in paid employment, there is only so much they can do. (V7)

We are not a professional…whether you are a doctor or a psychiatrist or psychologist you come with a label, so we're not a professional…and I think we just have time and flexibility, which sadly professionals don't because they have so many other things to do. (V5)

A further aspect of the relationship between client and volunteer was clients feeling able to take the lead and be more in control of the therapeutic process:

We sit down, have a chat and I'll then say "now come on (volunteer), we'll do something"…And then (volunteer) comes and does a bit more with me. Always with me, always with…(volunteer) never pushes me. (C2)

I accepted that I was a hoarder…I was up for it…It's always me to say "enough of the chat, let's get on with something"…so it's very much led by me and it's never, it's never led by what (volunteer) thinks we ought to do or what I should give away…it's all written down on forms as to where I want everything to go so I'm in control, which is brilliant. (C1)

This stance was echoed by volunteers, who identified that "*you are very much guided by the client*" (V6) and "*we are there specifically to help them at their own pace…we haven't got targets to meet*". (V7)

'Live life again'

Participants described how the project "*enables people to live their lives again…to get to a better place in their lives…to have hobbies…and make friendships*" (V3). One client described how the support he received "*means we can stay in our home*" (C2). Others described how the support from volunteers enabled clients to make space:

The most helpful thing has been being able to enjoy her home again…it's changed her life really I think…it was having huge impacts on her mental health and her mental wellbeing and being able to walk around and kind of have that clear space has given her that clear mind…she doesn't feel the need now to buy things and collect things and fill that space again. (V3)

I mean all of these bags and stuff have been sorted through and it's all here so I can get to things…It's a way of sorting out life…it's sorting out your life as well as your

belongings…I'm aware that it's going to be a long process, I mean, there is a lot of other stuff that is going to have to go and be sorted through. But there is now light at the end of the tunnel, because the journey has been started. (C1)

In addition to making space, clients described feeling supported and noted improvements to their overall psychological wellbeing and quality of life as a result of input from volunteers:

The difference is amazing…they have made an incredible psychological difference…it has given me back my, some self-respect. It's made me more positive. It's given me a purpose in life, it has potentially given me a way of making money…I can now stand up for myself more, it has given me confidence, self-confidence as well as self-respect…it's been life changing. It has been incredible. (C1)

It means sanity really…in terms of me, the impact on me is massive…you would go under, you would go under somehow (C4)

It helps us to cope with work I couldn't do on my own. If I tried to do this, well, I'd never get through! (C2)

Participants described how support from volunteers created a domino effect, enabling clients to address problems in other areas of their lives:

It has had such a wonderful knock on effect because she's being really resilient and is sorting out a lot of different problems in her life. (V2)

It's been a learning curve for me as well…I'm learning that, things that used to worry me, even a few months ago, I find I can just take it in my stride, keep things in perspective. (C2)

It enabled her to start something that she actually wanted to do but didn't know how to do it. (V3)

It's made a massive difference…I have gone through a stage of evolution really, so originally it was the decluttering…I've had to sort of move another area in my mind…instead of just decluttering, during the period you have been helping me, I haven't gone under. (C4)

Volunteers also described a sense of fulfilment and achievement from their work supporting clients, as well as a motivation to address difficulties in their own lives:

I am a people person, so, you know, I do, I do get quite a lot out of it…I do find it satisfying, rewarding…and exciting. (V5)

It makes me happy because I'm retired and I like something to do…we do it because we feel we are doing something useful and, it keeps us busy…I like to be involved and doing things so, that ticks that box rather well. (V1)

I enjoy it…it's exciting and I actually am interested in, sort of, the Psychology side of it…It has motivated me to do more clearing, so yes, I'm probably, yeah I'm gradually reducing the amount of stuff that I have, which is good. (V6)

Challenges

Participants described feelings of shame and embarrassment about the state that their home was in, as well as experiencing challenges with the physical environment that hindered the development of the therapeutic relationship:

I was so, ashamed and embarrassed about the state that it was in. And I used to worry for days ahead about people, who were coming in…I would start panicking seriously up to a week ahead, and hardly sleep the night before. (C1)

When I actually came to work with a client, I probably hadn't appreciated some of the, it's not health, but sort of hygiene aspects to the work…the moth infestations, it was a real challenge at times. (V6)

All participants reported difficulties in discarding possessions, including difficulties with access and having enough room to work:

Getting in the house! To manoeuvre into the front door to go into the room, the access to the room was difficult. (V4)

I had a bag for recycling, a bag for charity, which actually from a physical point of view is very difficult when there isn't much space. So to find enough room, to put the bags, to collect all the stuff in, and actually to just take the first suitcase out… (V6)

In terms of me clearing stuff out, it's sporadic in a way, it's quite difficult for me to concentrate on certain areas because it is everywhere really. (C4)

Letting go of possessions was also challenging for clients and was exacerbated by the physical limitations of some clients and volunteers:

He couldn't actually manoeuvre things…There were practical difficulties because of his stroke…my hearing isn't absolutely perfect so it was slightly difficult to engage with him. (V1)

Her main barrier was her health and her ability to move, so trying to encourage her to make space during the week when I wasn't there is not something that she could do. So I think her health and mobility was, yeah, a real barrier for her. (V7)

The thing that makes it difficult is actually getting rid of belongings…it's so traumatic…it is just so difficult for them, they just get so panicky and anxious…it was just too overwhelming for her…I think the challenging thing was, that she did find it very painful to let go of stuff. (V5)

However, one client described how her difficulties lay in finding a home for her discarded belongings:

I had a pile of VHS tapes and you can't get rid of them. They charge you, the shops won't touch them. (C3)

Finally, volunteers provided a number of examples of uncertainty about their work with clients and feelings of being kept 'at arm's length':

I never really knew whether I was going to get in or not…never quite sure if I would be let in…I was never really that confident, you know, of carrying on…The other frustrating thing is that she would move stuff around, so I was never quite sure what was happening! (V5)

What I found challenging was whether what they were saying was true. (V1)

I sort of found it a little, sort of, frustrating that she did in once sense keep me at arm's length…she was very suspicious about things. (V5)

Her paranoia about certain things...It's taken a long time to get that trust with her. And that was a barrier but that's something I had to just kind of keep plugging away at. (V2)

Supporting volunteers

Volunteers described a desire for additional training on the psychological aspects of working with compulsive hoarders, as well as training on how to manage some of the more practical aspects of the work:

Having had practical experience, there are aspects that would be useful to include like manual handling, talking about sort of the hygiene aspects…I think probably we could do with a little more awareness or training in terms of how we deal with it. (V6)

I'd like a little bit of training around the psychology of everything I think… just some guidance around those things, about how to deal with someone in this situation. (V3)

They also described the possibility of more joint working, including the possibility of developing a peer support group amongst volunteers:

I think that's quite important, two volunteers to go together. It would help because um, they may see things you don't…if you've got somebody who can go if you can't go for instance…two people see things differently. (V4)

I think that is absolutely key to the volunteers, to be able to offload it…There's a lot of Psychology involved in all this. It would be wonderful if there was opportunity for that sort of discussion. (V1)

Discussion

Little attention has been given to the experiences of individuals with hoarding disorder receiving help and those that provide help. Understanding the factors that act as barriers and facilitators in supporting people with hoarding disorder may be an important part of the solution to supporting people and increase service provision in the future. To this end, four key themes were identified in the current study. The relationship that formed between client and volunteer was crucial in providing a trusting foundation from which clients felt able to move forward. Volunteers provided a space for clients to talk, and reported that appropriate self-disclosure helped to build a relationship. The informal and 'non-professional' status of volunteers enabled clients to take the lead and feel more in control of the therapeutic process. Volunteer flexibility and lack of time constraints were also seen as important and contributed to clients 'making space' in their lives and in their homes. The support from the volunteers enabled clients to 'live life again' and created a domino effect, bringing about improvements in other areas of both of their lives. Shame and embarrassment represented a significant barrier to clients, as well as practical challenges in doing the work through lack of space or physical limitations. The need for providing support for the volunteers was also identified.

The current findings mirror previous research highlighting the importance of the therapeutic relationship (Ayers et al., 2012). Having space to talk, where clients had someone to talk to and felt heard was helpful in clients feeling less isolated. Kim, Steketee, and Frost (2001) reported that hoarders often experience social isolation and therefore input from projects such as the one described in the present study may help to broaden clients' horizons and reduce their sense of isolation. Switching the focus from hoarding and associated behaviours to the client as a person and their interests may also create a space for change and bring about improvements in clients' quality of life.

Although the importance of developing a therapeutic relationship is not new, this study highlights the significance of the 'non-professional status' of volunteers, which is consistent with previous findings that non-professionals may be helpful in enhancing clients' physical and mental wellbeing (Taft et al., 2011; Uhm et al., 2016). This has significant implications for services where their very status as 'professional' may act as a barrier to people with hoarding disorder engaging with them. Statutory services could therefore look to collaborate with third sector/charity organisations to offer peer/volunteer support alongside mainstream services. Evidence from the current research highlights benefits to both clients and volunteers by working in this way. However, the study highlighted the importance of ensuring volunteers feel supported in their work and mentoring or peer support may help to facilitate this. Moreover, the findings indicate the need for all people providing hoarding support to receive comprehensive training relevant to their role and highlights the importance of continued involvement of competent others to support and supervise the work of volunteers.

Control is an important factor in hoarding disorder (Raines, Oglesby, Unruh, Capron, & Schmidt, 2014) and the findings of this study provide further support. Clients feeling in control enabled them to feel able to start sorting and discarding their possessions. Volunteers in this study were also sensitive to the need of their clients to take the lead and feel in control regarding their possessions. This may help to both understand the reluctance amongst hoarders to seek help from formal services (Pertusa et al., 2010) and the importance of the 'volunteer' status in enabling a helping relationship to develop. Compared to working with mental health, social care, housing and environmental health services, for example, volunteers are less likely to be perceived as being in a position to threaten or remove the control that people with hoarding disorder have over their possessions. This is a difficult problem for services to solve. However, the current research highlights the importance of taking time to build a therapeutic relationship and that appropriate self-disclosure and discussion regarding shared interests may help.

Professionals may therefore benefit from making changes to their practice to adopt this approach; however, these changes are contingent on service providers recognising the value in this approach and creating space for professionals to work in this way.

It is understandable given the complexity and challenges associated with compulsive hoarding that many professionals struggle in their work (Holden et al., 2016). Although compulsive hoarders are widely considered to be a hard to reach and complex group, this study revealed positive outcomes when using volunteers in the absence of recognised cognitive behavioural strategies that have previously been highlighted as important (Ayers et al., 2012). A minimum of 50% reduction in CIRS scores was found in this study from first contact with clients to when volunteers were interviewed. Although this finding is not conclusive in itself, it suggests that non-professionals with a little training can produce positive outcomes with conventional outcome measures. Finally, as clients in this study were aged 63-88 years old, the findings have implications for professionals, services and organisations who work with older adults. Eckfield and Wallhagen (2013) reported significantly higher rates of hoarding in adults over 55 years old and according to service providers, hoarding behaviour posed a serious physical threat in 81% of their elderly clients (Kim, Steketee & Frost, 2001). The findings of this study highlight that taking time to build a therapeutic relationship, where older adults are able to take the lead and feel more in control of the therapeutic process, may help to reduce hoarding behaviours and lead to more positive outcomes in the longer term.

The present study has a number of methodological limitations. There was a dominance of female volunteers in the sample but this reflected the demographic of the volunteer pool. In light of the small sample (eleven participants) and recruitment from one organisation, the findings may have limited generalisability. Purposive sampling was adopted as the study aimed to explore the experiences of providing and receiving help within a small UK-based charity; however, it may be argued that those who agreed to participate were more motivated to share their experience and clients experiencing greater shame and embarrassment may have unintentionally been excluded (Kellett, 2007). In spite of adopting a number of validation methods and credibility checks, the analysis presented is the researchers' interpretation of the data and other interpretations and perspectives are possible. A strength of the study is that all participants completed established hoarding measures of either the SI-R (Frost et al., 2001) or CIRS (Frost et al., 2008) to confirm the presence of compulsive hoarding. This study is also the first study to directly explore the reciprocal experience of compulsive hoarders receiving and volunteers providing help. It is

a further strength that this study demonstrated an alignment in experience between the four clients interviewed and the volunteers who were working with them.

Conclusions and Implications

Compulsive hoarding continues to present significant challenges (Tolin et al., 2012), as well as economic, familial and social burden (Frost et al., 2000). The present study offers insights into how this could be improved and in particular highlights the importance of taking time to develop a therapeutic relationship and adopting a flexible and informal approach. By adopting this approach, this study found that volunteers with minimal training and people with hoarding disorder can develop meaningful and supportive relationships.

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Main Research Project

Posttraumatic growth in mothers 2-6 years after stillbirth and early miscarriage

Kirsty Ryninks
Doctorate in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: K.E.Ryninks@bath.ac.uk

Word count: 5318

May 2018

Internal/academic supervisors: Dr Megan Wilkinson-Tough; Doctoral Programme in Clinical Psychology
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: M.J.Wilkinson-Tough@bath.ac.uk

External/field supervisors: Professor Antje Horsch, Clinical Psychologist; Institute of Higher Education and Research in Healthcare, University of Lausanne and Department Woman-Mother-Child, University Hospital Lausanne, Switzerland
Email: Antje.Horsch@chuv.ch

Dr Sarah Stacey, Clinical Psychologist; HMP Bristol, 19 Cambridge Road, Bristol, BS7 8PS
Email: sarah.stacey1@nhs.net

Proposed Journal: BMC Pregnancy and Childbirth

Please see Appendix VII for instructions to authors

Introduction

Losing an unborn child is a very painful experience for a parent and may cause more intense grief than the loss of a partner or parent (Bonanno et al., 2002). Mothers may experience a variety of losses in pregnancy, including early miscarriage (EM; occurring in the first trimester of pregnancy up to 12 weeks), late miscarriage (LM; occurring during the second trimester at 13-23 weeks) and stillbirth (SB; defined as intrauterine death after 24 weeks gestation in the United Kingdom (UK)). Miscarriage affects 200,000 couples every year in the UK and 85% of all miscarriages occur in the first trimester. The global prevalence rate of SB in 2015 was 2.7 million (Lawn et al., 2016) and SB is estimated to occur in nearly 1 in 200 pregnancies (Martin, Kochanek, Strobino, Guyer, & MacDorman, 2005). In comparison to other types of child loss, pregnancy loss is often treated as less significant (Frøen et al., 2011) and parents are left feeling isolated and invalidated in their grief.

Losing a baby through miscarriage (Lee & Slade, 1996) or SB (Horsch, Jacobs, & McKenzie-McHarg, 2015) is recognised as traumatic (Kersting & Wagner, 2012). Part of the future is lost when a baby dies and bereavement reactions have been reported to be pervasive, powerful and complex (Cacciatore, 2010; Campbell-Jackson & Horsch, 2014; Robinson, 2011). Mothers are often unprepared for the loss and experience a range of psychological reactions, including denial, guilt, anger, grief and feelings of 'empty arms' (Adeyemi et al., 2008; Brownlee & Oikonen, 2004; Cacciatore, 2010; Murphy, Shevlin, & Elklit, 2014). Although the majority of mothers adjust and regain a sense of purpose, 15-25% seek additional support for enduring adjustment difficulties in the year after their loss (Bennett, Litz, Lee, & Maguen, 2005; Conway & Russell, 2000). In comparison to mothers of live babies, higher depressive and anxiety symptoms are more likely to be experienced by mothers for up to three years following the loss of their baby (Cacciatore, Rådestad, & Frederik Frøen, 2008). Mothers are also at risk of developing post-traumatic stress (Engelhard, van den Hout, & Arntz, 2001; Horsch et al., 2015), and experiencing high levels of affective disturbance in a subsequent pregnancy (Turton, Hughes, Evans, & Fainman, 2001).

Most studies to date have grouped different perinatal losses in their efforts to understand the psychological impact of loss in pregnancy. However, there are a number of differences between EM and SB and studies have highlighted that the psychological impact of these differing losses requires further clarification (Cacciatore & Bushfield, 2007; Klier, Geller, & Ritsher, 2002). Evidence suggests the further a pregnancy has progressed, the greater the attachment to the unborn child and more severe the grief reaction experienced by

the mother (Goldbach, Dunn, Toedter, & Lasker, 1991). Where loss in pregnancy is experienced early on, the loss often remains unacknowledged outside of the immediate family (Cacciatore, 2013; Kersting & Wagner, 2012). In contrast, as SB occurs after 24 weeks gestation, the pregnancy is visible due to significant physical changes in the appearance of the mother. In order to develop a deeper understanding of the psychological impact of miscarriage and SB, it is important to compare both losses within the same study (Cuisinier, Kuijpers, Hoogduin, De Graauw, & Janssen, 1993) and grouping perinatal loss is unlikely to be helpful (Campbell-Jackson & Horsch, 2014). Although this has been done by a few studies previously, findings are not consistent. For example, Toedter, Lasker, and Alhadeff (1988) found grief was more intense with greater gestational age at loss, whereas Smith and Borgers (1989) found no differences in grief between women who had experienced miscarriage compared to SB or neonatal death.

Apart from the distressing emotions that follow traumatic events, individuals may also experience positive psychological change (Tedeschi & Calhoun, 2004b). Posttraumatic Growth (PTG) is defined as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Calhoun & Tedeschi, 2001, p. 157). Through the journey to make sense of the world post-trauma, individuals may develop a greater appreciation for their relationships, have new spiritual insights, recognise their strengths and develop an acceptance that it is not always possible to prevent negative outcomes. Posttraumatic growth has "a quality of transformation or qualitative change in functioning" (Tedeschi & Calhoun, 2004b) and goes beyond an individual's previous adaption, psychological functioning or life awareness. Any positive changes arising in response to the trauma occur in conjunction with grief and distressing emotions that follow traumatic events, not in place of them (Tedeschi & Calhoun, 2004b). The phenomenon of PTG has been reported in individuals who have faced a variety of traumatic circumstances, including: natural disasters (Cryder, Kilmer, Tedeschi, & Calhoun, 2006), terrorism (Laufer & Solomon, 2006), cancer (Bellizzi, 2004), childhood sexual abuse (Wright, Crawford, & Sebastian, 2007), burn injuries (Rosenbach & Renneberg, 2008), war (Maguen, Vogt, King, King, & Litz, 2006), road trauma (Harms & Talbot, 2007) and HIV/AIDS (Milam, 2006). While the death of a loved one is devastating and painful, coping with bereavement has also been found to provide a context for significant positive change (Calhoun & Tedeschi, 1990; Engelkemeyer & Marwit, 2008; Mathews & Servaty-Seib, 2007). The possibility of PTG in the aftermath of pregnancy loss has received limited attention to date, with a focus historically on the more traumatic and distressing aspects of this loss. Black and Wright (2012) highlighted the need for systematic research on different perinatal losses (e.g., EM and SB) to clarify the posttraumatic responses these losses engender in bereaved parents.

One of the first studies to investigate PTG after pregnancy loss was conducted by Büchi et al. (2007). They investigated PTG in 54 parents who had lost their premature baby within the previous two to six years. Parents reported a shift in priorities about what is important in life, with the change appearing greater in mothers (78%) than fathers (44%). Wright (2010) used grounded theory with a sample of nineteen women who had experienced loss in pregnancy and found women felt more loving, compassionate and appreciative of the relationships they had. Black and Sandelowski (2010) conducted an ethnographic study to explore personal growth following severe fetal diagnosis and described that women and their partners found a new appreciation for life following their loss. More recently, Krosch and Shakespeare-Finch (2017) reported moderate levels of PTG (M=51.22, SD=20.13) on the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) in women who had experienced pregnancy loss. However, so far, PTG has not been investigated in detail following pregnancy loss and no study has explicitly compared PTG in SB and EM.

Calhoun, Tedeschi, Cann, and Hanks (2010) presented a Model of Growth in Grief to understand how losing "a close other" may result in the acknowledgment of a number of positive changes. Models of PTG focus on the degree to which the traumatic experience challenges world assumptions (Janoff-Bulman, 2006; Tedeschi & Calhoun, 2006). Deaths that are unexpected, less 'natural' and conflict with or disrupt an individual's assumptions and beliefs about the way the world should work (e.g. the death of a child) often result in more distress and PTG (Tedeschi & Calhoun, 2006). In addition to dealing with distress from losing a close other, the individual must reassess the principles of how they believe the world should work (Calhoun et al., 2010). Rumination has an important role to play as individuals attempt to reconstruct their beliefs following bereavement. Whilst this process can lay a foundation for growth and process of rebuilding (deliberate rumination), it can also initially add to distress (intrusive rumination) and negatively impact PTG (Calhoun & Tedeschi, 2006). Disclosure plays an important role, with supported self-disclosure helping individuals to manage distress and rebuild challenged assumptions about death and how the world should work (Calhoun et al., 2010).

The Model of Growth in Grief is of particular interest when considering loss in pregnancy, as the majority of published findings of positive changes following loss have focused on the loss of a loved one with whom one had an ongoing and longstanding relationship. Although mothers form attachments early on in pregnancy (Gold, Sen, & Hayward, 2010), mothers who experience loss in pregnancy do not have the opportunity to create direct life experiences with their baby, unlike in the death of close family members

(Kersting & Wagner, 2012). The pathway to PTG may therefore differ to other types of loss. Moreover, although mothers following EM and SB both experience loss in pregnancy, particular factors relating to the Model of Growth in Grief (challenge to assumptive beliefs (CAB), disclosure) may differ and result in differing levels of PTG. To our knowledge, no study has so far tested the Model of Growth in Grief using between-group comparisons. This study aimed to investigate PTG in mothers two to six years following SB compared to EM. It was hypothesised that mothers following SB will demonstrate more (1) PTG, (2) CAB, and (3) disclosure than mothers following EM. The study also aimed to investigate how theoretically-derived variables of the Model of Growth in Grief (CAB, rumination and disclosure) explain unique variance in PTG when key factors are controlled.

Method

Design

A cross-sectional between-groups design was adopted to compare PTG in mothers following SB and EM. The independent variable was type of loss (SB/EM) and primary dependent variable was PTG, with secondary dependent variables identified as key components from the Model of Growth in Grief (CAB, rumination and self-disclosure). The study was advertised and completed online. Ethical approval was granted by the University of Bath Psychology Ethics Committee (17-044).

Participants

The sample comprised 57 mothers in the SB group and 63 mothers in the EM group. Women were eligible to participate if they spoke English, were aged over 18 years old and had experienced either a SB at 24 weeks gestation or later (UK definition; Hughes & Riches, 2003) or an EM before 13 weeks gestation in the last two to six years. This time point was used previously by Büchi et al. (2007) and was established as sufficient time for PTG to have occurred. Women who had experienced a late miscarriage (between the 13th and 23rd week of pregnancy) were not included in this study due to concerns regarding feasibility, time constraints and greater heterogeneity across late miscarriage than in the EM or SB populations. Women were recruited online through advertisements placed on social media sites and through social media accounts of perinatal death charities. Data collection took place between November 2017 and March 2018.

Procedure

All questionnaires were completed online following reading of study information and provision of informed consent. For all questions referring to ‘the event’ or ‘the

incident', participants were asked to think about 'losing my baby'. If participants had experienced multiple losses in the previous two to six years, they were asked to answer the questions in relation to the loss (SB/EM) that affected them the most. Completing the survey took 30 minutes.

Materials

Emotional distress

Depressive symptoms. The Patient Health Questionnaire (PHQ-8; Kroenke & Spitzer, 2002) is an eight-item measure of depression with total score range of 0-24. The PHQ-8 omits the final item of the PHQ-9 which relates to thoughts about death or self-harm. It has comparable characteristics to the nine item version for diagnosing depressive disorders, with good test-retest reliability (α=.84) (Kroenke & Spitzer, 2002; Kroenke, Spitzer, & Williams, 2001; Kroenke et al., 2009). Cronbach's α for this study was .92.

Anxiety symptoms. The Generalised Anxiety seven-item scale (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006) is a seven-item measure of anxiety with total score range of 0-21. The GAD-7 has good reliability, as well as criterion, construct, factorial and procedural validity (Spitzer et al., 2006). Cronbach's α for this study was .91.

Grief symptoms. The Perinatal Grief Scale Short Version (PGS; Potvin, Lasker, & Toedter, 1989) is a 33-item scale with total score range of 33-165. Higher scores reflect more grief. Internal reliability of the total scale is excellent (Potvin et al., 1989), Cronbach's α=.94 (this sample α=.94). For the purposes of this study, only the total scale was used.

Posttraumatic stress disorder symptoms. The Posttraumatic Stress Disorder Checklist for DSM-5 (Weathers et al., 2013) is composed of 20 items that correspond to the 20 criteria for PTSD outlined in DSM-5. It contains four subscales corresponding to the four symptom clusters. For each item, a score of two or above is regarded as clinically relevant. The PCL-5 has demonstrated excellent internal consistency (α=.95) and strong divergent validity (Ashbaugh, Houle-Johnson, Herbert, El-Hage, & Brunet, 2016). For the purposes of this study, only the total scale was used. Cronbach's α for this study was .96.

Posttraumatic Responses and Disclosure

Posttraumatic Growth symptoms. The Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) is a 21-item scale with total score range of 0-105, where higher scores indicate more growth. It was designed to measure positive existential growth following traumatic events and consists of five subscales. In this study, the phrase 'your crisis' in the instruction was changed to 'losing your baby'. The PTGI has good internal consistency and

moderate test-retest reliability (Tedeschi & Calhoun, 1996). For the purposes of this study, only the total scale was used. Cronbach's α for this study was .94

Challenge to Assumptive Beliefs. The Core Beliefs Inventory (Cann et al., 2010) is a nine-item scale where participants rate the degree to which a recent highly stressful event led them to re-examine a number of core assumptions about themselves and their world. The total score range is 0-45. The CBI has construct validity, acceptable test-retest reliability, and very good internal consistency (Cann et al., 2010). Cronbach's α for this study was .92.

Disclosure of Trauma. The Disclosure of Trauma Questionnaire (DTQ; Müller, Beauducel, Raschka, & Maercker, 2000) is a 34-item self-report measure comprised of three subscales: 'reluctance to talk' (reported resistance to tell others about the trauma); 'urge to talk' (individual's need to disclose the traumatic experience); and 'emotional reactions' (descriptions of affective states experienced while disclosing the trauma). For the purpose of this study, the instructions for the DTQ were expanded to include 'in relation to losing your baby'. The DTQ has good psychometric properties, with Cronbach's α = 0.82 to 0.88 and retest reliability of 0.76 to 0.89 (Müller et al., 2000). For the current study, Cronbach's α reliability coefficients for the subscales were .81 (reluctance to talk), .88 (urge to talk), .87 (emotional reactions) and .89 for the total.

Actual Self-disclosure. In the absence of suitable formal published measures of actual self-disclosure, a set of questions was developed by the authors. Participants were asked to estimate the number of hours at three time points (first month, first year and second year after loss) they had spent talking to others (e.g. friends, family, healthcare staff or anyone else) about their feelings about losing their baby. They were also asked whether they had talked enough about their feelings about losing their baby at these time points. Actual self-disclosure was calculated by combining the total hours participants spent talking about their feelings about losing their baby in the first and second year after loss.

Rumination. The Event Related Rumination Inventory (Cann et al., 2011) is composed of two subscales containing ten statements relevant to intrusive rumination (IR) and ten statements relevant to deliberate rumination (DR). The total score range is 0-60. In this study, the instructions for the ERRI were changed from 'After an experience like the one you reported' to 'After a loss in pregnancy'. The ERRI has construct validity, acceptable test-retest reliability, and very good internal consistency (Cann et al., 2011). For the current study, Cronbach's α reliability coefficients for the subscales were .95 (IR), .92 (DR) and .95 for the total.

Statistical Analysis

A power analysis was conducted using G*power to calculate the sample size required to determine a statistical difference in PTG between the two groups. With an alpha of 0.05 and power of 0.80, the projected sample needed in each group was 51 participants for a moderate effect. Survey data was analysed using IBM SPSS Statistics version 23. Missing data points were identified in the actual disclosure variable, where 15 participants had not been able to estimate the amount of time they had spent talking about losing their baby. As this variable was considered very susceptible to individual differences, the missing data points were not substituted. Two outliers in actual self-disclosure were identified and excluded from analyses involving this variable. Descriptive statistics were used to describe the sample and all variables were assessed for outliers and violations of normality using histograms and skewness and kurtosis statistics. Where assumptions of normality were violated, equal variances were not assumed when testing for significance. Pearson's chi-square analyses and independent-samples t-tests were conducted to examine between-group differences that might affect or confound subsequent analyses. A hierarchical stepwise regression analysis was conducted to investigate how theoretically-derived variables of the Model of Growth in Grief (CAB, rumination, disclosure) explained unique variance in PTG when key factors were controlled for. The variables were entered in four steps in line with the development of PTG through the Model of Growth in Grief: 1) Confounds - age, type of loss (SB vs EM), PTSD symptoms and perinatal grief; 2) CAB; 3) Rumination - DR and IR; 4) Disclosure - urge to talk and actual self-disclosure.

Results

Participant Characteristics

Living children were reported in 96.5% of the SB group (N=55) and 87.3% of the EM group (N=55; see Table 3.1 for sample characteristics). Eleven participants in the SB group (19.3%) reported being pregnant at the time of completing the study compared to six participants in the EM group (9.5%). The mean time since loss was 3.23 years (SD=1.13) following SB and 3.19 years (SD=1.09) following EM. A total of 42.1% of participants in the SB group (N=24) and 57.1% in the EM group (N=36) had previously experienced loss in pregnancy. There were no significant differences between group and ethnicity, marital status, education, employment, being pregnant at the moment or having had a previous loss in pregnancy. However, more participants in the EM group (14.3%; N=9) compared to SB (1.8%; N=1) had previously experienced a late miscarriage ($\chi^2(1) = 6.15$, $p = .013$). A significant difference in age between the SB (M=34.74, SD=4.71) and EM groups (M=36.71, SD=5.36; t(118)=-2.14, p=.035) was also found.

Table 3.1 *Sample Characteristics (N = 120)*

	Stillbirth Mean (SD) or N (%)	**Early Miscarriage** Mean (SD) or N (%)	***p***
Age (years)	34.74 (4.71)	36.71 (5.36)	.035
Ethnicity			.392
White British	53 (93%)	57 (90.5%)	
Other White background	4 (7%)	3 (4.8%)	
Multiple/Mixed ethnic group	-	2 (3.2%)	
Other	-	1 (1.6%)	
Marital Status			.410
Single, never married	-	1 (1.6%)	
Married/civil partnership or cohabiting	56 (98.2%)	59 (93.7%)	
Divorced or separated	1 (1.8%)	3 (4.8%)	
Employment Status			.511
Full-time	14 (24.6%)	18 (28.6%)	
Part-time	26 (45.6%)	24 (38.1%)	
Student	-	2 (3.2%)	
Homemaker	16 (28.1%)	16 (25.4%)	
Other	1 (1.8%)	3 (4.8%)	
Education			.485
Left school without qualifications	-	1 (1.6%)	
GCSE qualifications or equivalent	4 (7%)	5 (7.9%)	
A-Level or equivalent	11 (19.3%)	8 (12.7%)	
Degree qualification or above	38 (66.7%)	48 (76.2%)	
Prefer not to say	1 (1.8%)	-	
Other	3 (5.3%)	1 (1.6%)	
Gestation of pregnancy loss			-
1-4 weeks	-	2 (3.2%)	
5-8 weeks	-	33 (52.4%)	
9-12 weeks	-	28 (44.4%)	
24-27 weeks	10 (17.5%)	-	
28-31 weeks	7 (12.3%)	-	
32-35 weeks	6 (10.5%)	-	
36-40 weeks	23 (40.4%)	-	
Over 40 weeks	11 (19.3%)	-	
Previous Pregnancy Loss			.100
Early Miscarriage	23 (40.4%)	34 (54%)	.136
Late Miscarriage	1 (1.8%)	9 (14.3%)	.013
Stillbirth	2 (3.5%)	2 (3.2%)	.919

SD standard deviation; *N* number of participants; *p* p-value

Descriptive statistics

Mean scores and standard deviations for all measures are provided in Table 3.2. Independent-samples t-tests revealed the SB group had significantly more perinatal grief ($t(118)=3.36$, $p<.001$) and PTSD symptoms ($t(117.97)=2.15$, $p=.034$) compared to EM. There were no significant differences in anxiety scores ($t(117.55)=1.38$, $p=.170$)) or depression scores ($t(117.98)=.09$, $p=.930$) between the groups.

Posttraumatic responses

Independent-samples t-tests revealed that compared to EM, the SB group had significantly greater PTG ($t(117.53)=3.19$, $p=.002$). Significant differences were found in IR ($t(118)=3.70$, $p<.001$) and DR ($t(118)=2.04$, $p=.043$) for SB compared to EM. There was also a significant difference in CAB for SB compared to EM ($t(117.78)=5.17$, $p<.001$).

Table 3.2. *Means (and standard deviations) for questionnaire scores by type of loss*

	Stillbirth Mean (SD)	**Early Miscarriage** Mean (SD)	***t***
GAD-7 (anxiety)	8.95 (5.65)	7.49 (5.877)	1.38
PHQ-8 (depression)	7.79 (6.28)	7.68 (7.043)	.09
PGS (perinatal grief)	98.05 (24.30)	81.97 (27.720)	3.36***
PCL5 (PTSD symptoms)	29.42 (19.30)	21.51 (21.034)	2.15*
DTQ (disclosure)	42.11 (16.97)	33.44 (15.719)	2.90**
DTQ – reluctance to talk	13.16 (8.66)	11.44 (8.890)	1.07
DTQ – urge to talk	13.68 (7.36)	10.00 (7.285)	2.75**
DTQ – emotional reactions	15.26 (7.70)	12.00 (6.816)	2.46*
Actual Self-disclosure (hours)	287.79 (317.78)	38.95 (69.266)	5.32***
ERRI (rumination)	35.84 (11.90)	27.52 (16.053)	3.20**
ERRI – intrusive rumination	17.88 (6.77)	12.62 (8.575)	3.70***
ERRI –deliberate rumination	17.96 (7.34)	14.90 (8.891)	2.04*
CBI (challenge to assumptive beliefs)	24.04 (9.08)	14.79 (10.491)	5.17***
PTGI (posttraumatic growth)	45.96 (23.31)	32.11 (24.195)	3.19**

SD standard deviation, *t* t-value, *GAD-7* Generalised Anxiety seven item scale, *PHQ-8* Patient Health Questionnaire, *PGS* Perinatal Grief Scale Short Version, *PCL-5* Posttraumatic Stress Disorder Checklist for DSM-5, *DTQ* Disclosure of Trauma Questionnaire, *ERRI* Event Related Rumination Inventory, *CBI* Core Beliefs Inventory, *PTGI* Posttraumatic Growth Inventory.
* $p < .05$, ** $p < .01$, *** $p < .001$

Disclosure

Significant differences in urge to talk ($t(116.55) = 2.75$, $p = .007$) and emotional reactions during disclosure ($t(118) = 2.46$, $p = .015$) were found in the SB compared to EM group. There was no significant difference in reluctance to talk between the two groups ($t(117.34) = 1.07$, $p = .287$). Compared to EM, the SB group had significantly more actual self-disclosure ($t(50.90) = 5.32$, $p < .001$). In the first month and year after losing their baby, a greater percentage of participants felt they did not talk enough about their EM (60.3% in first month (N=38); 55.6% in first year (N=35)) compared to participants following SB (47.4% in first month (N=27); 49.1% in first year (N=28)). In contrast, more participants following SB (59.6%, N=34) reported they did not talk enough in the second year after losing their baby compared to participants following EM (46%, N=29).

Variables predicting PTG

PTG was found to be significantly correlated with type of loss, $r(120) = -.28$, $p = .002$, CAB, $r(120) = .47$, $p < .001$, DR, $r(120) = .30$, $p = .001$, urge to talk, $r(120) = .54$, $p < .001$, reluctance to talk, $r(120) = -.19$, $p = .038$, and actual self-disclosure, $r(103) = .37$, $p < .001$. The following variables were not significantly correlated with PTG: PTSD symptoms, perinatal grief, depression, anxiety, IR, emotional reactions, previous loss in pregnancy, experiencing multiple losses in the last 2-6 years, having living children, being pregnant now, having a child since experiencing a pregnancy loss, age and time since pregnancy loss (see Table 3.3 for correlations of key variables).

The results of the hierarchical stepwise regression analysis are outlined in Table 3.4. Overall, 8.2% of variance in PTG was explained from step 1 (age, type of loss, PTSD symptoms and perinatal grief). CAB predicted an additional 17.6% in step 2. IR and DR predicted 5.9% in PTG in step 3 and urge to talk and actual self-disclosure predicted a further 14.7% in step 4. The final model explained 46.4% of variance in PTG, $F(9,93) = 8.93$, $p < .001$. Urge to talk ($\beta = .39$), CAB ($\beta = .38$) and actual self-disclosure ($\beta = .20$) significantly predicted PTG. The other variables were not found to make a unique contribution.

Table 3.3. *Correlations for SB and EM groups*

Measure	PTGI	Age	Type of Loss	Time since Loss	Child since Loss	PCL-5	PGS	CBI	ERRI Int.	ERRI Delib	DTQ Urge to Talk	DTQ Reluc to Talk
PTGI												
Age	-0.59											
Type of Loss	-.28***	.19*										
Time since Loss	-.11	.08	-.02									
Child since Loss	.14	.00	-.20*	.14								
PCL-5	.076	-.10	-.19*	-.07	-.23*							
PGS	.13	-.10	-.30**	-.03	-.23*	.79***						
CBI	.47***	-.05	-.43***	-.01	-.11	.46***	.56***					
ERRI Int	.16	-.07	-.32***	-.12	-.10	.76***	.68***	.37***				
ERRI Del	.30***	.05	-.19*	-.08	-.24**	.56***	.50***	.39***	.61***			
DTQ Urge	.54***	-.04	-.25**	-.12	.001	.27**	.30**	.39***	.34***	.45***		
DTQ Reluc	-.19*	-.13	-.10	.17	-.18*	.47***	.43**	.33***	.35***	.13	-.19*	
Actual Self-Disclosure	.37***	-.09	-.49***	-.05	.20*	.06	.14	.33***	.13	.12	.20*	-.12

PTGI Posttraumatic Growth Inventory, *PCL-5* Posttraumatic Stress Disorder Checklist for DSM-5, *PGS* Perinatal Grief Scale Short Version, *CBI* Core Beliefs Inventory, *ERRI* Event Related Rumination Inventory, *DTQ* Disclosure of Trauma Questionnaire.* $p < .05$, ** $p < .01$, *** $p < .001$

Table 3.4. *Multiple Regression Analysis: variables included in the regression model*

	B	***SE B***	***β***	***t***	***p***
Step 1					
Constant	54.20	21.24		2.55	.01
Age	-.02	.48	-.00	-.03	.97
Type of Loss	-13.06	5.08	-.27	-2.57	.01
PTSD symptoms	-.04	.19	-.03	-.21	.83
Perinatal grief	.07	.15	.07	.46	.65
Step 2					
Constant	42.45	19.35		2.19	.03
Age	-.15	.43	-.03	-.35	.72
Type of Loss	-5.10	4.88	-.10	-1.05	.30
PTSD symptoms	-.10	.17	-.08	-.59	.56
Perinatal grief	-.13	.14	-.14	-.93	.36
Challenge to assumptive beliefs	1.22	.26	.54	4.79	.00
Step 3					
Constant	38.31	19.05		2.01	.05
Age	-.32	.42	-.07	-.76	.45
Type of Loss	-3.55	4.92	-.07	-.72	.47
PTSD symptoms	-.32	.20	-.26	-1.61	.11
Perinatal grief	-.17	.14	-.18	-1.21	.23
Challenge to assumptive beliefs	1.17	.26	.51	4.61	.00
Intrusive Rumination	.31	.44	.10	.69	49
Deliberate Rumination	.79	.33	.27	2.39	.02
Step 4					
Constant	20.78	17.61		1.18	.24
Age	-.23	.38	-.05	-.61	.54
Type of Loss	1.18	4.79	.04	.37	.71
PTSD symptoms	-.23	.18	-.19	-1.28	.20
Perinatal grief	-.15	.12	-.17	-1.25	.22
Challenge to assumptive beliefs	.86	.24	.38	3.64	.00
Intrusive Rumination	.15	.40	.051	.39	.70
Deliberate Rumination	.36	.31	.12	1.17	.24
Urge to Talk	1.28	.29	.39	4.40	.00
Actual self-disclosure	.019	.01	.20	2.25	.03

B unstandardised beta, *SE B* standard error for unstandardised beta, *β* standardised beta (regression coefficient), *t* t-value, *p* probability.

Note R^2 = .082 for step 1; ΔR^2 = .176 for step 2 ($p < .001$); ΔR^2 = .059 for step 3 ($p < .05$); ΔR^2 = .147 for step 4 ($p < .001$)

Discussion

This study compared levels of PTG in mothers two to six years following SB or EM and examined whether theoretically-derived variables of the Model of Growth in Grief explained unique variance in PTG when key factors were controlled. Results indicated mothers who had experienced a SB experienced significantly greater PTG, PTSD symptoms and perinatal grief than mothers who had experienced an EM. Greater challenge to assumptive beliefs, intrusive and deliberate rumination, greater urge to talk and consequently greater reported actual self-disclosure were also found in mothers following SB compared to EM. The final regression model explained 46.4% of variance in PTG.

Higher levels of PTSD symptoms and PTG were found following SB compared to EM. A significant difference in PTSD symptoms was found between the two groups and gestational age has been reported to predict PTSD symptomatology (Engelhard et al., 2001). The differences in PTSD symptoms between SB and EM may also have been due to the greater physical trauma and perceived risk in SB, as well as the differences in prenatal attachment. Previous studies have reported PTG in mothers following SB (Goutaudier, Nahi, Boudoukha, Séjourné, & Chabrol, 2017), miscarriage (Isguder et al., 2017) and pregnancy loss in general (Büchi et al., 2009; Büchi et al., 2007; Krosch & Shakespeare-Finch, 2017). However, this is the first study we are aware of that explicitly compared PTG in a SB and EM population. Krosch and Shakespeare-Finch (2017) found higher levels of PTG following pregnancy loss (M=51.22, SD=20.13) than in the present study, which may be due to their longer time since loss (M=4.01 years compared to 3.23 (SB) and 3.19 (EM) in this study). There continues to be a paucity of research on the timeframe required for PTG to develop. Black and Sandelowski (2010) identified PTG in mothers within four months of perinatal loss and the present study replicated the time frame used by Büchi et al. (2007) in their study of PTG.

No significant differences between anxiety or depression were found between the groups, with mean scores in the mild range (Kroenke & Spitzer, 2002; Kroenke et al., 2009; Spitzer et al., 2006). Participants reported moderate to high levels of perinatal grief and scores were consistent with previous research (Toedter, Lasker, & Janssen, 2001) and findings that bereaved parents can experience grief for many years following their loss (Badenhorst & Hughes, 2007; Brier, 2008). Consistent with previous research (Clauss, 2009), higher grief scores were found in the SB group, further highlighting the distressing nature of this loss.

This is the first study to test the Model of Growth in Grief using a non-correlational design. Significant differences were found between the two groups, highlighting the importance of comparing types of loss within the same study. Significant group differences regarding CAB were found, suggesting SB is associated with a greater disruption of mothers' beliefs about the way the world should work than EM. These findings are consistent with theory (Calhoun et al., 2010; Tedeschi & Calhoun, 2006) and previous research highlighting the differences in CAB by gestational age (Krosch & Shakespeare-Finch, 2017).

Over half of mothers following EM felt they did not talk enough about their loss in the first month and year following their miscarriage, mirroring previous reports that EM remains shrouded in shame and silence and the difficulty mothers have in talking about their loss (Kluger-Bell, 2000). Mothers following SB disclosed greater urge to talk and reported greater actual self-disclosure than mothers following EM. Crawley, Lomax, and Ayers (2013) emphasised the importance of sharing memories of the stillborn baby to aid psychological adjustment and wellbeing, and disclosure appears to have been an important factor in the development of PTG in this study. However, the differences in disclosure may also reflect a lesser need for some mothers to talk about their EM than their SB, in keeping with the differences in CAB and reduced need to reconstruct beliefs following loss in pregnancy.

Individual differences, rather than the nature of the trauma (SB vs EM), were expected to determine rumination. However, significant differences in IR and DR were found between the two groups and may be the result of the differences in the visibility of the pregnancy, time spent pregnant, and expectations women hold of experiencing SB compared to EM. On average, mothers who had experienced an EM revealed higher levels of DR than IR. This is consistent with reports that intrusive thoughts are likely to occur in the immediate aftermath of an event, with deliberate thoughts occurring after the initial shock and distress subside (Black & Wright, 2012). It is therefore interesting that levels of IR and DR were comparable in mothers two to six years after experiencing a SB, which is a novel finding, and may relate to the physical trauma of SB.

Strengths and Limitations

A major strength of this study is the use of a between-groups design to investigate PTG in two groups of mothers following pregnancy loss (SB/EM), overcoming the limitations of previous correlational studies. Another strength is the application of theoretically-derived variables of the Model of Growth in Grief, the first of its kind in

relation to pregnancy loss. The findings provide support for the relevance of the variables in the Model of Growth in Grief (Calhoun et al., 2010) in the development of PTG in mothers following SB and EM. Finally, this study had a well-powered sample and used validated measures to capture key variables identified in the model.

This study has some limitations. In the absence of high-quality validated measures of actual disclosure (a problem encountered in other studies of PTG – see Pietruch and Jobson (2012)), a single-item measure of actual self-disclosure was created for this study. Single-item measures may not be sufficient to accurately measure a construct; however, in the design of this measure, attempts were made to help structure recall of time spent talking about loss. The large variability in responses may demonstrate problems with reliability and validity, but may also be an accurate reflection of individual differences in actual self-disclosure. The DTQ (Müller et al., 2000) was used to aid further understanding of disclosure; however, future research would benefit from developing a validated measure of disclosure to further test the Model of Growth in Grief.

As the majority of participants were White British who were married/civil partnership/cohabiting and educated to A-level or a degree qualification, the transferability of findings to other populations may be limited. Women who do not experience distress following pregnancy loss may not be as motivated to seek opportunities to participate in research. As the sample was self-selecting, it is likely that women who are interested in reflecting on their experience were more likely to participate. Online samples may therefore not be representative and results should be interpreted with caution. However, this is not a great concern here as 98.7% of people aged 16-44 have access to the internet (Office of National Statistics, 2016) and the sample reflected this age group.

The proportion of variance (46.4%) in PTG accounted for in this study indicates there are other factors contributing to its occurrence in mothers two to six years following SB and EM. The model suggests that the development of PTG will take time (involving a process of disclosure and rumination) and although this study replicated the 2-6 year time point used previously by Büchi et al. (2007), there is a lack of understanding in the literature of how time affects PTG and when levels may peak. Having a child since experiencing a pregnancy loss may also impact the development of PTG by potentially affecting the disclosure and rumination aspects of the Model of Growth in Grief. Time since loss and having a child since loss were not included in the regression model as they were not found to be significantly correlated with PTG. However, it is possible that these variables may help to explain a small proportion of the unaccounted variance in PTG. The current study's findings therefore raise further questions about which factors underpin PTG

following SB and EM and future research would benefit from exploring this. Finally, a limited number of confounding variables need to be considered. A greater percentage of mothers following EM had also experienced a LM (14.3%) compared to mothers following SB (1.8%) and the EM group were slightly older than the SB group.

Clinical Implications

Interventions targeting the key variables in the Model of Growth in Grief (CAB, disclosure and rumination) are likely to be clinically useful to promote psychological adjustment in mothers who have experienced SB and EM. The findings are therefore relevant to all practitioners who work with women following loss in pregnancy. In light of the finding that higher PTG and PTSD symptoms were found in mothers following SB than EM, it may be helpful to focus more resources on mothers who experience this type of loss. However, it is important to note that not all loss may result in PTG and some bereaved mothers may find the concept of growth offensive (Tedeschi & Calhoun, 2004a). Whilst PTG is common following trauma, it is not universal, and practitioners should not hold expectations that every mother will experience growth or that it is necessary for psychological adjustment to occur. Where mothers' beliefs have been seriously challenged, clinicians could work to support mothers to talk about their feelings about losing their baby and encourage greater disclosure with friends and family. Ultimately, there remains a need to change attitudes to pregnancy loss (especially EM) and disclosure at a societal level, rather than simply supporting mothers and their families through this type of loss.

Conclusions

Significantly higher levels of PTG, PTSD symptoms and perinatal grief were found in mothers following SB compared to EM. Mothers experienced greater challenges to their assumptive beliefs and revealed higher levels disclosure following their SB. These findings can partially be explained by differences in key variables from the Model of Growth in Grief.

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Executive Summary

Losing an unborn child is a very painful experience for a parent and may cause more intense grief than the loss of a partner or parent (Bonanno et al., 2002). Mothers may experience a variety of losses in pregnancy, including early miscarriage (EM; occurring in the first trimester of pregnancy up to 12 weeks gestation), late miscarriage (LM; occurring during the second trimester at 13-23 weeks) and stillbirth (SB; defined as intrauterine death after 24 weeks gestation in the United Kingdom (UK)). Miscarriage affects 200,000 couples every year in the UK and 85% of all miscarriages occur in the first trimester. SB is estimated to occur in nearly 1 in 200 pregnancies (Martin, Kochanek, Strobino, Guyer, & MacDorman, 2005). In comparison to other types of child loss, pregnancy loss is often treated as less significant (Frøen et al., 2011) and parents are left feeling isolated and invalidated in their grief.

Losing a baby through miscarriage (Lee & Slade, 1996) or stillbirth (Horsch, Jacobs, & McKenzie-McHarg, 2015) is recognised as a traumatic event (Kersting & Wagner, 2012). Part of the future is lost when a baby dies and bereavement reactions have been reported to be pervasive, powerful and complex (Cacciatore, 2010; Campbell-Jackson & Horsch, 2014). Mothers are often unprepared for the loss and experience a range of psychological reactions, including denial, guilt, anger, grief and feelings of 'empty arms' (Adeyemi et al., 2008; Brownlee & Oikonen, 2004; Cacciatore, 2010; Murphy, Shevlin, & Elklit, 2014). Most studies to date have grouped different perinatal losses in their efforts to understand the psychological impact of loss in pregnancy. However, there are a number of factors that are different between EM and SB and studies have highlighted that the psychological impact of these differing losses requires further clarification (Cacciatore & Bushfield, 2007; Klier, Geller, & Ritsher, 2002).

Individuals who face traumatic experiences often experience a number of distressing emotions, including anxiety, sadness, anger, guilt, depression and desire for a different outcome (Tedeschi & Calhoun, 2004). However, through the journey to make sense of the world post-trauma, evidence suggests that many individuals experience psychological change which they consider to be positive. The phenomenon of PTG has been reported in a wide range of individuals who have faced a variety of traumatic circumstances. While the death of a loved one is a devastating and painful experience, coping with bereavement has also been found to provide a context for significant positive change (Calhoun & Tedeschi, 1990; Engelkemeyer & Marwit, 2008; Mathews & Servaty-Seib, 2007). The possibility of PTG in the aftermath of pregnancy loss has received limited attention to date, with a focus historically on the more traumatic and distressing aspects of

this loss. Black and Wright (2012) highlighted the need for "systematic research on different types of perinatal loss" (e.g. EM and SB) to clarify the posttraumatic "responses that these losses engender" in bereaved parents (p. 233).

Calhoun, Tedeschi, Cann, and Hanks (2010) presented a Model of Growth in Grief to understand how losing "a close other" may result in the acknowledgment of a number of positive changes. Deaths that are unexpected, less 'natural' and conflict with or disrupt an individual's assumptions and beliefs about the way the world should work (e.g. the death of a child) often result in more distress and PTG (Tedeschi & Calhoun, 2006). The Model of Growth in Grief is of particular interest when considering loss in pregnancy, as the majority of published findings of positive changes following loss have focused on the loss of a loved one where there has been a longstanding and ongoing relationship. Although mothers form attachments early on in pregnancy (Gold, Sen, & Hayward, 2010), mothers who experience loss in pregnancy do not have the opportunity to create direct life experiences with their baby, unlike in the death of close family members (Kersting & Wagner, 2012). The pathway to PTG may therefore differ to that found in other types of loss.

This study aimed to investigate PTG in mothers two to six years following SB, compared to in mothers following EM. It also aimed to investigate how theoretically-derived variables of the Model of Growth in Grief (challenge to assumptive beliefs, rumination and disclosure) explain unique variance in PTG when key factors are controlled. The study recruited 120 women who had experienced a SB (57) or EM (63) in the last two to six years. Participants completed questionnaires on emotional distress, disclosure and posttraumatic responses in an online survey. Results indicated that mothers who had experienced a SB experienced significantly greater PTG, posttraumatic stress symptoms and perinatal grief than mothers who had experienced an EM. Greater challenge to assumptive beliefs, intrusive and deliberate rumination, greater urge to talk and consequently greater reported actual self-disclosure were also found in mothers following SB compared to EM.

This is the first study we are aware of that explicitly compared PTG in a SB and EM population. It is also the first study to test the Model of Growth in Grief using a non-correlational design. Interventions that target key variables in the Model of Growth in Grief (challenge to assumptive beliefs, disclosure and rumination) are likely to be clinically useful to promote psychological adjustment in mothers who have experienced SB and EM. The findings are therefore relevant to all clinicians who work with mothers following loss in pregnancy. It must be noted however that whilst PTG is common following trauma, it is not universal, and clinicians should not hold expectations that all mothers will experience PTG or that it is required for psychological adjustment to occur. Ultimately, there remains a need

to change attitudes to pregnancy loss (especially EM) and disclosure at a societal level, rather than simply supporting mothers and their families through this type of loss.

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Connecting Narrative

Overview

This connecting narrative aims to integrate the research projects that have been completed as part of the DClinPsy at the University of Bath. Undertaking these projects has been one of the most enjoyable parts of training. The narrative will first consider the case studies completed on the course before discussing and reflecting on the broader themes characterised by the service improvement project, main research project and critical review of literature.

Case studies

Over the course of clinical training, I completed five case studies across my working age adult, older adult, child, learning disability and adult health placements. The case studies provided valuable research skills and enabled me to draw on theory to make clinically relevant conclusions. Four of the five case studies were cognitive behavioural in their approach, but also drew upon or considered other therapeutic approaches (e.g. third wave CBT/systemic). One case study was written purely from a systemic perspective and provided a welcome lens into alternative ways of formulating with clients and the systems supporting them. Across all case studies, the importance of the therapeutic relationship was highlighted and this theme connects the case studies to my service improvement project.

My first case study highlighted the benefit of including timeline generation in an extended CBT formulation to provide an effective base from which to work on Body Dysmorphic Disorder (BDD) using CBT. Having worked prior to training in an Improving Access to Psychological Therapy (IAPT) service, I was confident in my ability to deliver CBT. However, I was soon struck by the severe and enduring nature of the difficulties I was working with. Working with clients in a secondary care mental health service proved very different and significantly more challenging than anything I had done previously. My first case study therefore taught me the importance of the therapeutic relationship and interventions being client-led. Developing a timeline together and making sense of the past in light of a BDD diagnosis was an important first step and helped to build the therapeutic relationship. Although it would have been helpful to utilise a measure examining the therapeutic relationship directly, the use of idiosyncratic measures throughout the therapy revealed improvements that were not captured by more formal outcome measures. This case study was accepted as a poster at the British Association for Behavioural and Cognitive Psychotherapy 2016 conference in Belfast.

The second case study was completed on my older adult placement in a community-based later life therapies team. I integrated a compassion-focussed approach with CBT to treat low self-esteem and depression experienced by an older woman in the context of physical health difficulties and anxiety about the future. A single case experimental design (SCED) was adopted to evaluate the effectiveness of therapy. This was my first experience of using a SCED and taught me the benefits of using session-by-session measures to monitor progress and outcomes of therapy. Once again, making sense of the past (including consideration of early life experiences and intergenerational beliefs) was an important part of the therapy and lack of social contact/support was identified as an important factor in the maintenance of my client's difficulties. I embraced the slower pace of the work and enjoyed the space to reflect and freedom that this brought in therapy.

My third case study also highlighted the therapeutic relationship as important and focused on supporting an adolescent with chronic headaches to learn to take steps to live alongside her pain. Anxiety-specific CBT was introduced first before using the three pillars of Acceptance and Commitment Therapy (ACT) as a way of engaging in flexible and persistent patterns of values-directed behaviour, whilst in contact with continuing pain. A SCED was used once more to evaluate the intervention and I enjoyed the opportunity to learn more about ACT. Systemic factors were identified as important in this case, which also played a key role on my next placement in a community team for people with learning disabilities.

The fourth case study adopted a systemic approach with a residential staff team to support a woman with Down's Syndrome and moderate intellectual disability experiencing bereavement. This taught me about the importance of working with the systems around people with learning disabilities and raised questions about stigma and discrimination. Developing a trusting and therapeutic relationship with the staff team opened a space for more positive stories about the resident to develop. Staff were left feeling empowered and resourceful and reflecting upon unique outcomes helped to break up the problem-saturated story. I enjoyed the opportunity to work in a different way on this placement and will take this learning forward into my career as a qualified Clinical Psychologist.

The fifth case study explored the utility of transdiagnostic CBT with a patient presenting with generalised anxiety, depression and health anxiety in the context of chronic kidney disease. The case shared similarities with my child and older adult case studies, where psychological distress was also associated with physical health difficulties. A SCED was adopted and completing outcome measures each week enabled progress to be more accurately tracked, including which transdiagnostic interventions resulted in change. Once

again, the therapeutic relationship was an important factor in the patient's willingness to try new ideas.

Service Improvement Project

I first came across my service improvement project (volunteers' experiences of helping hoarders and hoarders' experiences of being helped) at the research fair and it turned out to be the largest project that I completed on clinical training. I was excited about the prospect of working with a charity rather than service in the NHS, as I am aware of the lack of support that charities often have when evaluating and developing their services. I also had an interest in understanding more about the charity's Making Space project and the positive outcomes that had been reported. The service improvement project began with a meeting with the charity's Director of Development (Dan Lyus), Making Space project coordinator (Nia Hall) and my internal supervisor (Dr James Gregory). Together we identified the key aims of the service improvement project and developed a plan to conduct 1:1 interviews with volunteers and clients from the Making Space project.

As the Making Space project was part of a charity, NHS ethical approval was not required and all project documentation was approved by the University of Bath Ethics committee in June 2016. Eleven interviews with clients and volunteers were conducted over the following 18 months. The period of recruitment was significantly longer than anticipated as we faced challenges recruiting clients. Unfortunately, the charity did not have permission to contact a number of previous clients and therefore recruitment had to allow for new clients to be seen by volunteers before they could be interviewed. This experience taught me the importance of patience and flexibility when conducting research! However, in spite of the challenges recruiting clients, I really enjoyed conducting the interviews and meeting the clients and their volunteers. It was a privilege to be invited into clients' homes and hear their stories of how they had developed a problem accumulating and discarding numerous possessions, as well as the difference that the Making Space project had made to their lives. My previous experience of conducting interviews (including qualitative analysis) was invaluable and I enjoyed becoming immersed in the interview data. It was also helpful for a second supervisor, Dr Vuokko Wallace, to join the project prior to the analysis phase and she provided valuable input into the qualitative analysis.

A number of themes were developed and resulted in specific recommendations for the charity, including the need to provide more support for volunteers. The relationship that formed between client and volunteer was crucial in providing a trusting foundation from which clients felt able to move forward. This theme echoed my experiences on placement,

where I have found the therapeutic relationship to be a hugely important part of my work with clients. A peer support group for volunteers has since been developed and it has been really pleasing to see the charity include a number of quotes from clients and volunteers in their project information and applications for additional funding. Being involved in this project really highlighted the difference that third sector organisations can make and it was a privilege to work alongside the charity as they work to grow the Making Space project for the future.

Main Research Project and Critical Review of Literature

As a scientist-practitioner, I believe it is important to actively contribute to the evidence-base and for the evidence-base to inform my clinical practice. I chose to focus most of my research on training in the field of clinical health as this is where the majority of my experience prior to clinical training had been. I was fortunate to work previously on a national project exploring maternal contact with the stillborn infant and developed a number of contacts in perinatal health. I also worked on a project in the Paediatric Intensive Care Unit (PICU) at Bristol Children's Hospital that saw me come into contact with most wards within the hospital. It was from these experiences that the ideas for my main research project and critical review of literature developed. The two projects share the theme of physical health and adjustment.

Critical Review of Literature

In a meeting with my clinical tutor, Dr Cara Davis, I was reminded of some of the difficulties I had come into contact with during my 2.5 years working at Bristol Children's Hospital. Part of my role had involved visiting the cardiac ward to recruit families who had been admitted to PICU following life-saving cardiac treatment. I had been struck by the reactions of patients and their families to their cardiac scar, with a huge variety of responses from disgust to pride. I was keen to find out more about psychological reactions to scarring following cardiac surgery but soon found that there had been very little research to date. Even after broadening the literature search to include other types of planned surgery, it was agreed that there were too few papers to conduct a systematic literature review or meta-analysis.

I began to explore the vast field of visible difference which revealed a wealth of literature in relation to psychological adjustment where disfigurement already existed or where it had occurred through injury. It appeared that less was known about adjustment when treatment had been planned (e.g. surgery). A meeting with my internal supervisors (Professor Paul Salkovskis and Dr Cara Davis) led to the decision to write a conceptual

review that incorporated the existing literature on scarring with research from the visible difference literature to develop a new model to understand psychological adjustment to scarring following planned surgery.

The process of writing the conceptual review was incredibly daunting and challenging as I had not embarked on a project like this before. It was also unclear what the process of writing this type of review would involve and I had to embrace a position of uncertainty, something I have never enjoyed doing! However, reassurance and support from my two internal supervisors and Dr Nell Ellison (Clinical Psychologist for Paediatric Cardiology Services) enabled me to enjoy the process of generating new theoretical knowledge. I found the process of developing a new model exciting and found it particularly rewarding to develop a number of practical recommendations for health professionals working in physical health settings. My previous experience at Bristol Children's Hospital highlighted the importance of preparing and supporting patients through their surgery and resultant scarring and I was pleased that this review offered some suggestions for how multidisciplinary teams might do this. Writing the conceptual review was inspired by my experience in health prior to training, similar to my main research project.

Main Research Project

I was keen for my main research project to focus on the area of perinatal health as this is an area I have always been interested in. I was already in contact with a past research supervisor, Professor Antje Horsch, who is very experienced in conducting research and working clinically with women who have experienced perinatal loss. We had worked together prior to clinical training on a large scale national project interviewing women who had experienced a stillbirth. This experience proved invaluable as I sought to immerse myself in the area of perinatal loss once again.

Through a number of skype meetings with my internal supervisor (Dr Megan Wilkinson-Tough) and two external supervisors (Professor Antje Horsch and Dr Sarah Stacey), we agreed to investigate emotional reactions to loss in pregnancy. I was particularly interested in understanding more about the positive changes that might occur as a result of loss in pregnancy, as this was a theme that had emerged from the interviews I had conducted with mothers previously. However, settling on the two comparison groups proved very challenging, as it did not feel appropriate to use a control group of women who had not experienced pregnancy loss, nor to compare pregnancy loss to another type of bereavement. In light of my interest in how disclosure may be involved in the development

of posttraumatic growth, I chose to investigate posttraumatic growth in mothers who had experienced an early miscarriage and mothers who had experienced a stillbirth.

It was important to include people with personal experience in the design of the project, especially as the project was going to be hosted online and therefore involve no direct contact with the research team. The project replicated the time point used in a previous study on perinatal loss and therefore meant that recruiting through the NHS would not be possible as local services did not have permission to retrospectively contact patients. I knew that the process of obtaining IRAS approval was often confusing, slow and frustrating, so I was relieved that I did not have to go through IRAS to recruit through the NHS. However, in hindsight, I wonder if this was a missed opportunity for valuable learning and practice for the future. As I intend to continue conducting research in my qualified practice, I look forward to learning this skill.

I met early on with a couple who had experienced a stillbirth and later a woman who had experienced several early miscarriages. Both meetings highlighted how vital service user consultation is and provided valuable feedback on the project and associated documentation. The Stillbirth and Neonatal Death Charity (Sands) were consulted regarding study documentation and agreed to support and advertise the project. Although I had some apprehension about how mothers might interpret questions relating to positive changes that they may have experienced following their loss, this did not arise as an issue at any stage of the project. The greatest surprise and challenge was instead the backlash that came from bereaved parents who did not meet the eligibility criteria for the study. I was aware of the sensitivity surrounding loss in pregnancy but was not prepared for the intensity nor negativity of the comments that were posted on the Sands Facebook page in the hours after they first posted information about the project. This served as a valuable learning opportunity for me and for Sands, and highlighted the lack of awareness in the general population about the need for inclusion and exclusion criteria in research studies. It also brought home the reality of using social media to advertise research and the negative consequences of instant messaging. Sands have since developed a webpage explaining why studies need inclusion and exclusion criteria in research and they are in the process of creating a separate page away from their Facebook group to advertise research studies in the future. Subsequent posts by Sands in support of the project did not generate further negative comments and to my surprise, our recruitment target was exceeded as we recruited a total of 120 mothers.

Summary

I believe my training on the Bath course has put me in an excellent position to continue undertaking research in my future career as a qualified Clinical Psychologist. Undertaking the research components of the course has been one of the most enjoyable aspects of clinical training. I have found conducting research incredibly rewarding and valued the opportunity to explore a number of areas in detail using multiple research methodologies, rather than researching one topic. However, conducting multiple research projects alongside working full-time was stressful and frustrating at times as I felt I could not give my full attention to each project. I hope that my dedicated half day per week for continuous professional development and research in my first qualified post will help to ease this pressure in the future.

Across all the case studies, the importance of the therapeutic relationship was highlighted and this theme connected my case studies to my service improvement project. My main research project and critical review of literature were both conducted in the field of clinical health and shared the theme of physical health and adjustment. Conducting three research projects and five case studies on the course has taught me a great deal about research design and conduct and I believe this variety of research designs and methodologies will stand in me in good stead as I start my next chapter in qualified practice.

Finally, the course has taught me the equal value and importance of undertaking service improvement, large scale research and single case experimental designs in order to grow and develop the evidence base in Clinical Psychology. I am committed to being an evidence-based practitioner who contributes to the evidence base. I am grateful for the variety of experiences I have had on placement to practice new skills, apply theory to practice and write up examples of my clinical work. I have valued the involvement of people with personal experience in my research and the opportunity to write up the findings for publication. I hope that my research will make a valuable contribution to the evidence base and be useful to clinicians in the future.

Acknowledgments

First and foremost, I would like to express how indebted I am to my husband Tim for his unwavering support through the ups and downs of clinical training. His love, patience and constant belief in me has given me the motivation to keep going. I hope I can one day repay all the support he has given me over the last three years. I would also like to thank my family, friends and fellow trainees for all their support through clinical training.

I wish to thank Dr Cara Davis, my Clinical Tutor, for overseeing my professional and personal development and generally being a huge support in time of need throughout the course. I would also like to thank all of my placement supervisors (Dr Kerry Ozcelik, Dr Hen Joannidi, Dr Rebecca Guhan, Dr Chloe Constable, Dr Samantha Green, Dr Suzanne Whitehead, Dr Kate Druett, Dr Leon Dysch and Marion Dixon) for their support in completing my case studies and developing my clinical skills. Working alongside these inspiring supervisors has motivated me to be the best Clinical Psychologist I can be.

I have been fortunate to have four incredibly supportive and passionate academic supervisors for my three research projects on clinical training. I am grateful to Professor Paul Salkovskis, who supported me through the daunting and challenging journey of writing a conceptual literature review. I would also like to thank Dr Cara Davis and Dr Nell Ellison for their encouragement and involvement in the review. I am grateful to Dr James Gregory for the opportunity to conduct a service improvement project in a third sector organisation and to further refine my skills in qualitative methodology. I would also like to thank Dr Megan Wilkinson-Tough, Professor Antje Horsch and Dr Sarah Stacey for their support in continuing my interest in perinatal health. In spite of the challenges that were faced along the way, this was my favourite project on training. I hope that my findings will make a real difference to the lives of mothers and their families who have experienced loss in pregnancy in the future.

Finally, I would like to thank all the clients that I had the privilege to work alongside and participants who agreed to take part in my research. Without their involvement, I wouldn't be where I am today.

Kirsty Ryninks

University of Bath

May 2018

Appendices

Appendix I: Instructions for Authors – Body Image

BODY IMAGE
An International Journal of Research

ELSEVIER

AUTHOR INFORMATION PACK

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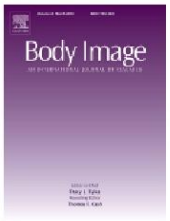

ISSN: 1740-1445

DESCRIPTION

Body Image is an international, peer-reviewed journal that publishes high-quality, scientific articles on **body image** and human **physical appearance**. Body image is a multi-faceted concept that refers to persons' perceptions and attitudes about their own body, particularly but not exclusively its appearance. The journal invites contributions from a broad range of disciplines - psychological science, other social and behavioral sciences, and medical and health sciences. The journal publishes original research articles, brief research reports, theoretical and review papers, and science-based practitioner reports of interest. The journal gives an annual award for the best doctoral dissertation in this field.

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•Body image and physical appearance in diverse cultural contexts;
•Validation of assessments of the multidimensional body image construct;
•Factors that influence positive and negative body image development;
•Adaptive and maladaptive body image processes and their clinically relevant consequences on **psychosocial** functioning and quality of life;
•Relationship of body image to **behavioral** variables (e.g., exercise and other physical activity, eating and weight-control behaviors, grooming and appearance-modifying behaviors, and social behaviors);
•Scientific evaluation of interventions to promote positive body image or to prevent or treat body image difficulties and disorders.

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To: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>;

Dear Kirsty,

Thank you for your email.

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Many thanks,

Orla Davies
Rights Assistant
John Wiley & Sons Ltd

WILEY

From: Kirsty Ryninks [mailto:K.E.Ryninks@bath.ac.uk]
Sent: 23 January 2018 17:10
To: Wiley Global Permissions <permissions@wiley.com>
Subject: NON RIGHTSLINK - Permission to reproduce image

From: Kirsty Ryninks
Sent: 23 January 2018 17:04
To: mailto:
Subject: Permission to reproduce image.

To whom it may concern,

I have been trying to request permission through your website to reproduce an image from one of your book titles but I am having difficulty locating the "Request Permissions" link as outlined in your guidance (http://wileyrights.gmss.sg/wiley_content.php).

I would like to request permission to reproduce Figure A.11 on page 270 of your book titled "CBT for Appearance Anxiety: Psychosocial Interventions for Anxiety due to Visible Difference" by Alex Clarke et al.

The image will be included in my doctoral portfolio as part of my training at the University of Bath, as well as in a review article I have been writing with Dr Paul Salkovskis that we intend to submit for publication.

Would you be happy for us to include this image in our review article? And how can we go about obtaining this permission?

We look forward to hearing from you.

Kind Regards,
Kirsty Ryninks

Clinical Psychologist in Training, University of Bath

Appendix III: Copyright permission (The cognitive behavioural model of Body Dysmorphic Disorder) – David Veale

5/5/2018 Re: Permission to reproduce Figure - Kirsty Ryninks

Re: Permission to reproduce Figure

Kirsty Ryninks

Mon 22/01/2018 14:38

To: Veale, David <david.veale@kcl.ac.uk>;

Dear David,

Thank you for your email giving permission to reproduce and sending the book chapter.

I think we will reference the 2004 article as that is the image we have used in the development of our model. However, we would like to reference the 2017 chapter in the review itself. Thank you for bringing it to our attention.

Best Wishes,
Kirsty

From: Veale, David <david.veale@kcl.ac.uk>
Sent: 21 January 2018 14:04
To: Kirsty Ryninks
Subject: Re: Permission to reproduce Figure

Yes of course although you may be interested in an updated book chapter published in 2017 see Figure 23.1
Baldock E, Veale D, (2017). The self as an aesthetic object: a model of cognitive processing in Body Dysmorphic Disorder. Phillips, K.A. (editor). Oxford University Press. Chapter 23. pp. 299-310

David

From: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>
Date: Wednesday, 17 January 2018 at 14:52
To: David Veale <david.veale@kcl.ac.uk>
Subject: Permission to reproduce Figure

Dear David,

You may remember meeting with me, Cara Davis and Paul Salkovskis at Bath University to discuss the review article we have been working on looking at psychological adjustment to scarring following planned surgery.

We are planning to submit the article we have written to Body Image to be considered for publication and would like to request permission to reproduce Figure 1 (A cognitive behavioural model of BDD) from the following article:

Veale, D. (2004). Advances in a cognitive behavioural model of body dysmorphic disorder. *Body image, 1*(1), 113-125.

Please let us know if you are willing to grant this permission.

I look forward to hearing from you.

Kind Regards,
Kirsty Ryninks

Clinical Psychologist in Training, University of Bath

Appendix IV: Instructions for Authors – British Journal of Clinical Psychology

Author Guidelines

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to

use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

• The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading 'Practitioner Points'.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manualpublished by the American Psychological Association.

If you need more information about submitting your manuscript for publication, please email Vicki Pang, Editorial Assistant (bjc@wiley.com) or phone +44 (0) 1243 770 410 (ex 434 10).

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table

or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

7. Copyright and licenses

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

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If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs.

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

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To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

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8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded **here**.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found athttp://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript.
Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site: http://www.adobe.com/products/acrobat/readstep2.html.

This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

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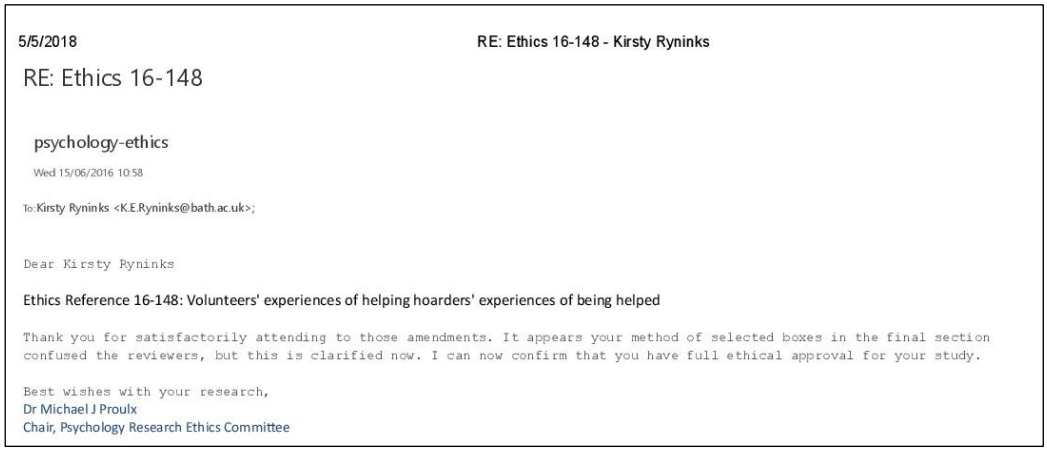
Appendix V: University of Bath Service Improvement Project Ethical Approval



5/5/2018 RE: Ethics 16-148 - Kirsty Ryninks

RE: Ethics 16-148

psychology-ethics

Wed 15/06/2016 10:58

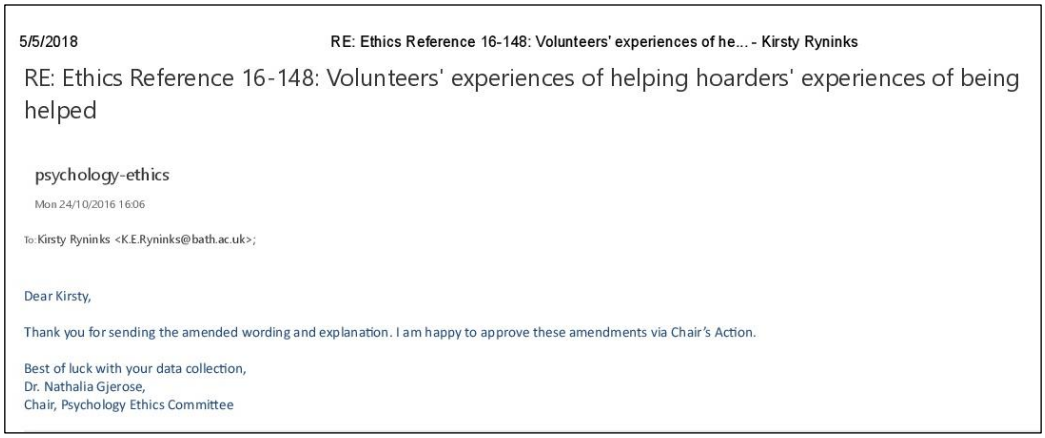
To: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>;

Dear Kirsty Ryninks

Ethics Reference 16-148: Volunteers' experiences of helping hoarders' experiences of being helped

Thank you for satisfactorily attending to those amendments. It appears your method of selected boxes in the final section confused the reviewers, but this is clarified now. I can now confirm that you have full ethical approval for your study.

Best wishes with your research,
Dr Michael J Proulx
Chair, Psychology Research Ethics Committee



5/5/2018 RE: Ethics Reference 16-148: Volunteers' experiences of he... - Kirsty Ryninks

RE: Ethics Reference 16-148: Volunteers' experiences of helping hoarders' experiences of being helped

psychology-ethics

Mon 24/10/2016 16:06

To: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>;

Dear Kirsty,

Thank you for sending the amended wording and explanation. I am happy to approve these amendments via Chair's Action.

Best of luck with your data collection,
Dr. Nathalia Gjerose,
Chair, Psychology Ethics Committee

Appendix VI: Service Improvement Project Study Materials (Client and volunteer/case worker: Information Sheet, Consent Form, Demographic Questionnaires, Debrief Sheet)

CARE&REPAIR

Version 2: **13.10.16**

Department of **Psychology**

UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation

Client Information Sheet

Context

WE Care and Repair have supported many people who have accumulated numerous possessions and this led them to develop the Making Space project in February 2015. Making Space uses a volunteer peer support model to work with clients in their own homes. The project has a practical focus on the physical environment to improve the safety and quality of life of adults who have accumulated numerous possessions in their homes. Volunteers work to motivate and support clients to 'make space' in their home.

Why is this study being done?

About 2-4% of the population experience difficulties associated with accumulating numerous possessions and it can cause many problems in people's lives, such as with their family, their ability to work and to maintain social contacts. People often find it difficult to obtain or seek help and WE Care and Repair appear to be an organisation that people have found they can engage with.

It is important that WE Care and Repair understand the experience of delivering and receiving their Making Space project from both staff/volunteers and clients. This will help the service to keep doing the things that it's doing well and change the things that it's not doing so well. Consequently, we are asking WE Care and Repair staff/volunteers and clients if they can spare a little of their time to tell us about their experiences.

Before you decide to take part, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why have I been asked to take part?

We are contacting you because we understand you have received support from WE Care and Repair. We would like you to join in an evaluation of the service that the Making Space project provides to clients through WE Care and Repair.

Do I have to take part?

No. Participation in this project is voluntary. If you do not wish to take part, this will not change the service that you are offered in any way. If you decide to take part and then later change your mind, either before you start the project, during it or afterwards, you can withdraw without giving your reasons, and, if you wish, your data will be destroyed up until the point of it being fully anonymised.

What will I be asked to do if I take part?

The project will involve completing two questionnaires about difficulties associated with accumulating numerous possessions (these should take about 10-15 minutes). You will then be asked to share your experience of receiving a service from WE Care and Repair in relation to accumulating numerous possessions in an interview (about 30-60 minutes) conducted by Kirsty Ryninks (Trainee Clinical Psychologist) at the St Philips office of WE Care and Repair, University of Bath or in your home, whichever is easiest for you. The interview will be recorded so that we can listen to what you have said at a later date and you would be welcome to receive a copy of the recording if you wanted one. The recording will be transcribed verbatim for analysis but identifiable details will be removed and all the information you provide will be anonymised.

Will my experiences and reports be kept confidential?

Yes. All information collected about you during the course of the project will be kept confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. This means that all paper-based and electronic information will be locked and password protected with access restricted to project personnel and any information about you will have your name and address removed so that you cannot be identified from it.

We plan to report our findings in academic related journals and also present them to professionals at meetings, workshops and conferences. We would like to share the information we learn from this project so that other organisations can better support their clients who accumulate numerous possessions. This can make people a little apprehensive but we can assure you that you will not be identifiable in any reports or publications arising from the project.

Are there any advantages/benefits from taking part?

This study will not help you directly but the information collected from you and other participants should help to improve our understanding of the service provided by WE Care and Repair. Our aim from conducting this, and other studies like it, is to help develop and improve the services that WE Care and Repair offer to clients.

Are there any disadvantages/risks from taking part?

We consider there to be minimal disadvantages (e.g. the inconvenience of completing the questionnaires and/or being interviewed).

What to do next if I'm interested or have some questions?

If you would like to find out more about taking part or have any questions about anything that you have read, please return the attached opt-in form by email to K.e.ryninks@bath.ac.uk or by posting to Doctorate in Clinical Psychology, Building 10 West 3.42, Claverton Down, Bath, BA2 7AY. You may also find it helpful to discuss this project with WE Care and Repair and they can pass on your details for us to contact you directly.

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 1: 23.05.16

Department of Psychology | UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation: understanding people with hoarding difficulties experiences of being helped and volunteers' experience

Making Space Volunteer/Case Worker Information Sheet

Context

WE Care and Repair have supported numerous people with hoarding difficulties and this led them to develop the Making Space project in February 2015. Making Space uses a volunteer peer support model to work with adults that hoard in their own homes. The project has a practical focus on the physical environment to improve the safety and quality of life of adults who hoard. Volunteers work to motivate and support clients to de-clutter and improve their environment at home.

Why is this study being done?

About 2-4% of the population experience hoarding difficulties and it can cause many problems in people's lives, such as with their family, their ability to work and to maintain social contacts. People often find it difficult to seek help and WE Care and Repair appear to be an organisation that people have found they can engage with.

It is important that WE Care and Repair understand the experience of delivering and receiving their Making Space project from both staff/volunteers and clients. This will help the service to keep doing the things that it's doing well and change the things that it's not doing so well. Consequently, we are asking WE Care and Repair staff/volunteers and clients if they can spare a little of their time to tell us about their experiences.

Before you decide to take part, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why have I been asked to take part?

We are contacting you because we understand you are involved in working with hoarders through WE Care and Repair. We would like you to join in an evaluation of the service that the Making Space project provides to clients through WE Care and Repair.

Do I have to take part?

No. Participation in this project is voluntary. If you do not wish to take part, this will not change your role in the service in any way. If you decide to take part and then later change your mind, either

before you start the project, during it or afterwards, you can withdraw without giving your reasons, and, if you wish, your data will be destroyed up until the point of it being fully anonymised.

What will I be asked to do if I take part?

The project will involve completing two questionnaires about hoarding (these should take about 10-15 minutes). You will then be asked to share your experience of receiving a service from WE Care and Repair in relation to hoarding difficulties in an interview (about 30-60 minutes) conducted by Kirsty Ryninks (Trainee Clinical Psychologist) at the St Philips office of WE Care and Repair or in your home, whichever is easiest for you. The interview will be recorded so that we can listen to what you have said at a later date and you would be welcome to receive a copy of the recording if you wanted one. The recording will be transcribed verbatim for analysis but identifiable details will be removed and all the information you provide will be anonymised.

Will my experiences and reports be kept confidential?

Yes. All information collected about you during the course of the project will be kept confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. This means that all paper-based and electronic information will be locked and password protected with access restricted to project personnel and any information about you will have your name and address removed so that you cannot be identified from it.

We plan to report our findings in academic/health related journals and also present them to health professionals at meetings, workshops and conferences. We would like to share the information we learn from this project so that other organisations can better support their clients who hoard. This can make people a little apprehensive but we can assure you that people will not be identifiable in any reports or publications arising from the project.

Are there any advantages/benefits from taking part?

This study will not help you directly but the information collected from you and other participants should help to improve our understanding of the service provided by WE Care and Repair. Our aim from conducting this, and other studies like it, is to help develop and improve the hoarding related services that WE Care and Repair offer to clients.

Are there any disadvantages/risks from taking part?

We consider there to be minimal disadvantages (e.g. the inconvenience of completing the questionnaires and/or being interviewed).

What to do next if I'm interested or have some questions?

If you would like to find out more about taking part or have any questions about anything that you have read, please return the attached opt-in form by email to K.e.ryninks@bath.ac.uk or by posting to Doctorate in Clinical Psychology, Building 10 West 3.42, Claverton Down, Bath, BA2 7AY. You may also find it helpful to discuss this project with WE Care and Repair and they can pass on your details for us to contact you directly.

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 2: 13.10.16

Department of Psychology

UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation

Opt-in Form

WE Care and Repair is working in partnership with the University of Bath. We would like you to join in an evaluation of the service that the Making Space project provides through WE Care and Repair.

If you are interested in taking part in this project and participating in a brief interview about your experience, please tick the box and fill in your contact details.

☐ I would be happy to be contacted by Kirsty Ryninks (Trainee Clinical Psychologist) using the information I have provided below.

Name: _____

Email: _____

Telephone: _____

Signature: _____

Please return this form by email to K.e.ryninks@bath.ac.uk or by posting to Doctorate in Clinical Psychology, Building 10 West 3.42, Claverton Down, Bath, BA2 7AY.

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 2: 13.10.16

Department of Psychology | UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation:

Consent Form

	Please initial all boxes
1. I confirm that I have read and understood the information sheet dated 13.10.16 (version 2) for the above project. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary, that I am free to withdraw at any time without having to give a reason, and that my decision will not affect my employment/care/legal rights.	☐
3. I understand that any information about me will be handled in confidence. Any analyses and reports or publications (including short quotations in the media) from the data will be summary data only and will not identify me.	☐
4. I give consent for my interview to be taped for the purposes of later transcription and for the researchers to ensure the quality of the interviewing process.	☐
5. I agree to take part in the project.	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 2: 13.10.16

Department of Psychology
UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation:

Demographic Questionnaire – Client

To help us understand the information from the interview, please tell us a little bit about you.

Please complete/tick the relevant boxes below.

Age	_____ years old
Gender	☐ Male ☐ Female
Marital Status	☐ Single ☐ In Relationship ☐ Married ☐ Separated ☐ Divorced ☐ Widowed
Employment Status	☐ Full-time ☐ Part-time ☐ Retired ☐ Home maker ☐ Looking for work/unemployed ☐ Other (specify): _____
What is your ethnic group?	☐ White UK ☐ White Irish ☐ Black Caribbean ☐ Black African ☐ Chinese ☐ Bangladeshi ☐ Indian ☐ Pakistani ☐ Mixed/Multiple Ethnic Background (specify): _____ ☐ Other (specify): _____

What is your highest level of Education?	☐ GCSE or equivalent ☐ A-level or equivalent ☐ Bachelors degree ☐ Masters degree ☐ Other (specify): _____
Does anyone else live with you at home?	☐ Yes ☐ No If Yes, please give details:
Do you think you have/have had a problem accumulating numerous possessions?	☐ Yes ☐ No If Yes, when do you think this became a problem? ☐ Childhood ☐ Adolescence ☐ In my 20s ☐ In my 30s ☐ In my 40s ☐ In my 50s ☐ In my 60s ☐ In my 70s ☐ Other (specify): _____
Have you ever received help from a health professional for problems relating to accumulating numerous possessions?	☐ Yes ☐ No If Yes, how many times have you received help and when was this? What kind of support did you receive and for how long? Overall, how helpful was this support on a scale of 1 to 10, 1 being "not helpful at all" and 10 being "extremely helpful"?

Are you currently taking any medication in relation to difficulties accumulating numerous possessions?	☐ Yes ☐ No (Please Specify if Yes):
How many visits did you have with a Making Space volunteer?	
How long, on average, did the visits last?	
Over approximately how many months did your visits last?	
Overall, how helpful were the visits with the Making Space volunteer on a scale of 1 to 10, 1 being "not helpful at all" and 10 being "extremely helpful"?	

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 1: 23.05.16

Department of Psychology
UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation: understanding people with hoarding difficulties experiences of being helped and volunteers' experience:

Demographic Questionnaire – Making Space Volunteer/Case Worker

To help us understand the information from the interview we need to know a little bit about you.

Please complete/tick the relevant boxes below.

Age	_____ years old
Gender	☐ Male ☐ Female
Employment Status	☐ Full-time ☐ Part-time ☐ Retired ☐ Home maker ☐ Looking for work/unemployed ☐ Other (specify): _____
What is/was your occupation?	
What is your ethnic group?	☐ White UK ☐ White Irish ☐ Black Caribbean ☐ Black African ☐ Chinese ☐ Bangladeshi ☐ Indian ☐ Pakistani ☐ Mixed/Multiple Ethnic Background (specify): _____ ☐ Other (specify): _____

What is your highest level of Education?	☐ GCSE or equivalent ☐ A-level or equivalent ☐ Bachelors degree ☐ Masters degree ☐ Other (specify): _____
Did you have any experience of working with people with hoarding difficulties prior to becoming a case worker/ volunteer?	
How long have you been a case worker/volunteer with the Making Space project?	
Have you undertaken any training that has helped you to work with clients in the Making Space project?	☐ Yes ☐ No If Yes, please give details:
Approximately how many clients have you worked with?	

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Version 2: 13.10.16

Department of Psychology
UNIVERSITY OF BATH

Building 10 West 3.42
Claverton Down
Bath BA2 7AY

Email: k.e.ryninks@bath.ac.uk

Making Space Project evaluation

Debrief Sheet

Thank you for taking part in this project. WE Care and Repair have supported many people who have accumulated numerous possessions and want to understand the experience of delivering and receiving their Making Space project from both the perspective of their staff/volunteers and clients. Your support in this project will help the service to keep doing the things that it's doing well and change the things that it's not.

If you would like to receive a written summary of the findings of the project when that becomes available, please either email K.E.Ryninks@bath.ac.uk or ask WE Care and Repair to request this.

We have prepared a list of resources for participants who have taken part in the project so that you are aware of what options are available if you feel you would like some additional support. Please note that we do not expect you to be looking for support but we wanted to keep this list as comprehensive as possible. The list is not exhaustive however and we cannot specifically recommend each book/website/service or guarantee the quality of each.

Books and Websites

Overcoming Compulsive Hoarding: Why you Save & How you Can Stop, by Fugen Neziroglu, Jerome Bubrick and Jose Yaryura-Tobias.

www.helpforhoarders.co.uk	Help for Hoarders - this informative site was developed to provide information, support and advice and create awareness about this secretive condition, for hoarders and their loved ones. The website contains a resources page with additional resources to those listed here.
www.hoardinguk.org	Hoarding UK offer phone, email and advocacy support free of charge.

Thank you very much for your time and your support in helping us to continue to improve the service that WE Care and Repair and the Making Space project provide.

Appendix VII: Service Improvement Project Outcomes

As the charity is currently undergoing a reorganisation and retendering process, providing formal feedback on this project has been difficult due to other more pressing priorities for the charity. The charity has received a copy of the project report and feedback has been given informally by email and telephone calls.

The charity has been contacted regarding presenting the findings to volunteers within the Making Space project and the wider organisation and this formal feedback will be given at their volunteer meeting on 12th September 2018.

The informal feedback that has been given to the charity to date has resulted in the following:

- Quotations from the interviews with clients and volunteers have been used in promotional material about the Making Space project and to support applications for additional funding for the project.

- The training package for volunteers is under review and the charity plans to include additional information on manual handling/hygiene in the future. The charity are also exploring the possibility of further training on the psychological aspects of working with compulsive hoarders.

- A peer support group for volunteers has been established and the feedback to date has been positive, with volunteers feeling more supported in their work with hoarders.

- The data collected from the CIRS and SI-R has been of interest to the charity and a consultancy project is currently exploring how to incorporate outcome measures into the project in the future.

Appendix VIII: Instructions for Authors –BMC Pregnancy and Childbirth

Research article

Criteria

Research articles should report on original primary research, but may report on systematic reviews of published research provided they adhere to the appropriate reporting guidelines which are detailed in our editorial policies. Please note that non-commissioned pooled analyses of selected published research will not be considered.

BMC Pregnancy and Childbirth strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible. Please see Springer Nature's information on recommended repositories. Where a widely established research community expectation for data archiving in public repositories exists, submission to a community-endorsed, public repository is mandatory. A list of data where deposition is required, with the appropriate repositories, can be found on the Editorial Policies Page.

Authors who need help depositing and curating data may wish to consider uploading their data to Springer Nature's Research Data Support or contacting our Research Data Support Helpdesk. Springer Nature's Research Data Support provides data deposition and curation to help authors follow good practice in sharing and archiving of research data, and can be accessed via an online form. The services provide secure and private submission of data files, which are curated and managed by the Springer Nature Research Data team for public release, in agreement with the submitting author. These services are provided in partnership with figshare. Checks are carried out as part of a submission screening process to ensure that researchers who should use a specific community-endorsed repository are advised of the best option for sharing and archiving their data. Use of Research Data Support is optional and does not imply or guarantee that a manuscript will be accepted.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
    - or for non-clinical or non-research studies a description of what the article reports
- list the full names, institutional addresses and email addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the “Acknowledgements” section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- BACKGROUND: the context and purpose of the study
- METHODS: how the study was performed and statistical tests used
- RESULTS: the main findings
- CONCLUSIONS: brief summary and potential implications
- TRIAL REGISTRATION: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and material
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval.

See our editorial policies for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our editorial policies for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.

BioMed Central also requires that authors cite any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare.
2014. http://dx.doi.org/10.6084/m9.figshare.853801

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each author's competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding

All sources of funding for the research reported should be declared. The role of the funding body in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript should be declared.

Authors' contributions

The individual contributions of authors to the manuscript should be specified in this section. Guidance and criteria for authorship can be found in our editorial policies.

Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

See our editorial policies for a full explanation of acknowledgements and authorship criteria.

If you do not have anyone to acknowledge, please write "Not applicable" in this section.

Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the submission system and also include collaborating author names as the last paragraph of the “Acknowledgements” section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or

country information for each author if you wish, but this should be consistent across all authors.

Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

Authors' information

This section is optional.

You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

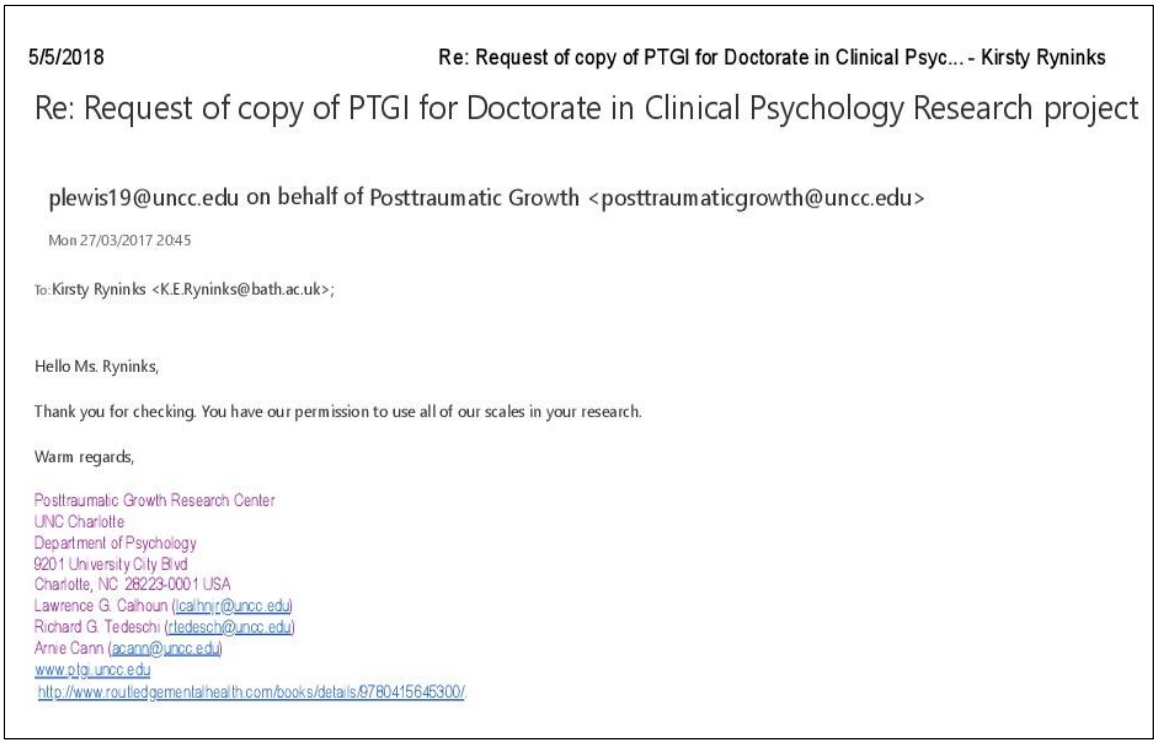
Endnotes

Endnotes should be designated within the text using a superscript lowercase letter and all notes (along with their corresponding letter) should be included in the Endnotes section. Please format this section in a paragraph rather than a list.

References

All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. The reference numbers must be finalized and the reference list fully formatted before submission.

Appendix IX: Permission to use questionnaires from Posttraumatic Growth Research Centre



5/5/2018 Re: Request of copy of PTGI for Doctorate in Clinical Psyc... - Kirsty Ryninks

Re: Request of copy of PTGI for Doctorate in Clinical Psychology Research project

plewis19@uncc.edu on behalf of Posttraumatic Growth <posttraumaticgrowth@uncc.edu>

Mon 27/03/2017 20:45

To: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>;

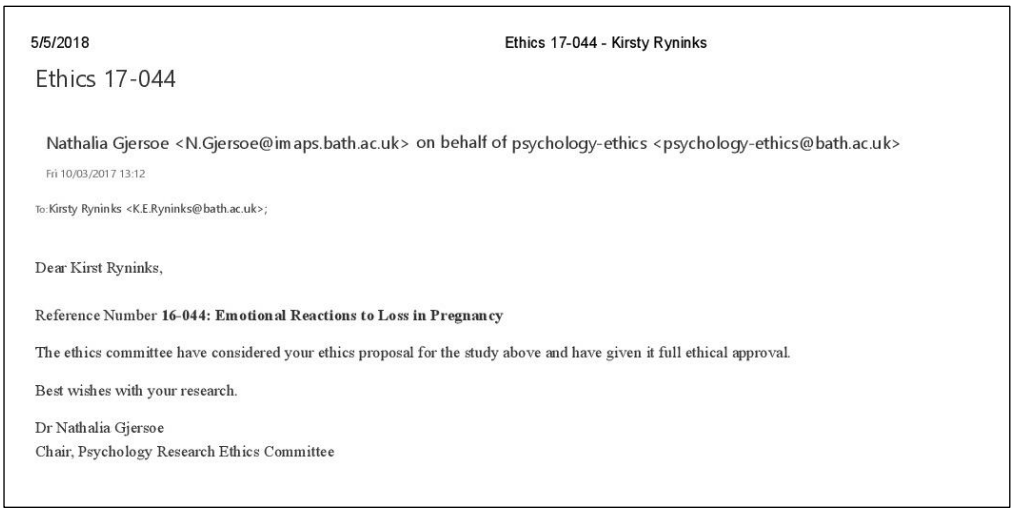
Hello Ms. Ryninks,

Thank you for checking. You have our permission to use all of our scales in your research.

Warm regards,

Posttraumatic Growth Research Center
UNC Charlotte
Department of Psychology
9201 University City Blvd
Charlotte, NC 28223-0001 USA
Lawrence G. Calhoun (lcalhoun@uncc.edu)
Richard G. Tedeschi (rtedesch@uncc.edu)
Arnie Cann (acann@uncc.edu)
www.ptgi.uncc.edu
http://www.routledgementalhealth.com/books/details/9780415645300/

Appendix X: University of Bath Main Research Project Ethical Approval



5/5/2018 Ethics 17-044 - Kirsty Ryninks

Ethics 17-044

Nathalia Gjersoe <N.Gjersoe@imaps.bath.ac.uk> on behalf of psychology-ethics <psychology-ethics@bath.ac.uk>

Fri 10/03/2017 13:12

To: Kirsty Ryninks <K.E.Ryninks@bath.ac.uk>;

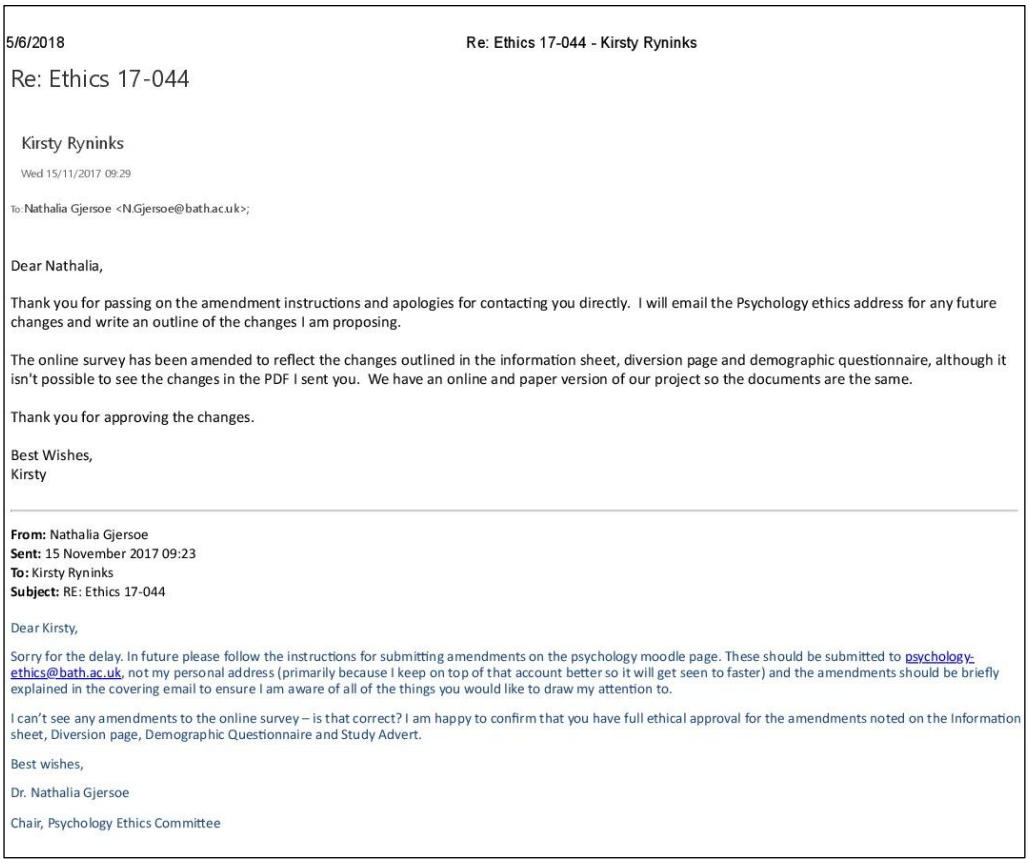
Dear Kirst Ryninks,

Reference Number **16-044: Emotional Reactions to Loss in Pregnancy**

The ethics committee have considered your ethics proposal for the study above and have given it full ethical approval.

Best wishes with your research.

Dr Nathalia Gjersoe
Chair, Psychology Research Ethics Committee



5/6/2018 Re: Ethics 17-044 - Kirsty Ryninks

Re: Ethics 17-044

Kirsty Ryninks

Wed 15/11/2017 09:29

To: Nathalia Gjersoe <N.Gjersoe@bath.ac.uk>;

Dear Nathalia,

Thank you for passing on the amendment instructions and apologies for contacting you directly. I will email the Psychology ethics address for any future changes and write an outline of the changes I am proposing.

The online survey has been amended to reflect the changes outlined in the information sheet, diversion page and demographic questionnaire, although it isn't possible to see the changes in the PDF I sent you. We have an online and paper version of our project so the documents are the same.

Thank you for approving the changes.

Best Wishes,
Kirsty

From: Nathalia Gjersoe
Sent: 15 November 2017 09:23
To: Kirsty Ryninks
Subject: RE: Ethics 17-044

Dear Kirsty,

Sorry for the delay. In future please follow the instructions for submitting amendments on the psychology moodle page. These should be submitted to psychology-ethics@bath.ac.uk, not my personal address (primarily because I keep on top of that account better so it will get seen to faster) and the amendments should be briefly explained in the covering email to ensure I am aware of all of the things you would like to draw my attention to.

I can't see any amendments to the online survey – is that correct? I am happy to confirm that you have full ethical approval for the amendments noted on the Information sheet, Diversion page, Demographic Questionnaire and Study Advert.

Best wishes,

Dr. Nathalia Gjersoe

Chair, Psychology Ethics Committee

Appendix XI: Main Research Project Study Materials (Information Sheet, Consent Form, Demographic Questionnaire, Study Questionnaires, Debrief Sheet)

Version 3: **07.11.17**

Department of Psychology | UNIVERSITY OF BATH

EMOTIONAL REACTIONS TO LOSS IN PREGNANCY

Information Sheet

Context

We would like to invite you to take part in our research project exploring emotional reactions to loss in pregnancy. Before you decide whether or not you would like to take part, it is important to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends and family if you wish. If you have any questions about this project, please contact the research team on erlp@bath.ac.uk

Why is this study being done?

Miscarriage and stillbirth are unique and painful experiences and each person will experience different emotional reactions. We are interested in understanding more about these emotional reactions. We hope that the outcomes of this project will improve our understanding and enable us to improve the help and support offered to women and their families following early miscarriage and stillbirth.

Who can take part in this project?

We know that all parents' experiences of the death of their baby or babies are important to understand and explore. But to make sure we are asking good research questions and that we can make good sense of our findings, we have to be very specific about who takes part in this project. We are therefore focusing on certain groups of women and certain types of loss in this project. As we are following on from some earlier research, we are using the same timeframe that was used in the original work.

We are particularly interested in understanding the emotional reactions of the following groups of women in the UK and who are currently over the age of 18 years old:

- Women who experienced a **stillbirth (at 24 weeks of pregnancy or later)** 2 to 6 years ago
- Women who experienced an **early miscarriage (up to 12 weeks of pregnancy)** 2 to 6 years ago

Unfortunately, we are unable to invite the following groups to take part in this project at this time:

- Women who are currently under the age of 18 years
- Women who cannot read English because we are unable to translate the questionnaires
- Women who experienced a late miscarriage (between the 13th and 23rd week of pregnancy) 2 to 6 years ago
- Women who lost their baby more recently than 2 years or more than 6 years ago** (see below)

Women who have had a pregnancy loss (early miscarriage or stillbirth) 2 to 6 years ago **and a more recent loss **are able** to take part (as we will ask about the loss that affected you most in the last 24 months to 6 years).

[N. B. Women who have had a more recent loss but have not lost a baby in the 2-6 year time frame are not eligible for this particular study, but we hope we can do more research in this area in the future].

What will I be asked to do if I take part?

The project will involve completing a number of questionnaires online about yourself, your pregnancy loss and your emotional wellbeing. If you would prefer to complete the questionnaires by hand, please email the research team at erlp@bath.ac.uk with your address and a copy of the survey questions will be sent to you in the post to complete anonymously and return in a stamped addressed envelope. Completing the survey is expected to take 30 minutes.

If you complete the survey online, we suggest that you use a device that you can easily type on and complete the survey at a time when you can be quiet and will not be disturbed. You will have the option to have a break and come back to the online survey by clicking on the "finish later" option at the bottom of each page. This will enable you to either bookmark the survey or to have the details emailed to you. All responses will be anonymous.

At the end of the study, we will ask some brief questions about your experience of taking part in the research. It is important to remember that there are no right or wrong answers to the questions as each individual's experience will be different.

Do I have to take part?

Participation in this project is voluntary. It is up to you to decide whether you wish to take part in the project or not. You can contact the research team by emailing erlp@bath.ac.uk if you would like to speak further before deciding whether or not you would like to take part. We aim to respond to all emails within a week.

Are there any advantages/benefits from taking part?

We cannot promise that this project will help you directly but we hope that the information we collect will improve our understanding of emotional reactions following early miscarriage and stillbirth and improve the help and support that is offered to women and their families in the future. Previous research has shown that some people have found it helpful to take part in studies about their experiences and felt as though they were helping others by sharing their experiences. On completion of the project, a summary of our findings will be made available to participants who wish to receive them. You can request this by emailing erlp@bath.ac.uk.

Are there any disadvantages/risks from taking part?

Completing our survey will require you to think about thoughts and feelings that some people might find challenging. It is possible that you may find answering questions about your loss upsetting. This is a normal reaction when thinking about difficult experiences and such feelings will normally subside within a short time. It is important for you to understand that you are not required to answer questions or share anything that you do not want to.

If you are worried about your wellbeing, please make an appointment with your General Practitioner (GP). You could also contact other services that offer support and a list of helpful addresses and resources is available at the end of this information sheet. All your responses will be anonymous and so it will not be possible for the research team to identify who you are and whether your answers suggest you may be feeling anxious or depressed. If you have any concerns about your participation in the research, please contact a member of the research team by emailing erlp@bath.ac.uk If you wish, we can arrange for someone to call you to discuss your concerns within three working days.

Will my experiences be kept confidential?

Yes. All information collected about you during the course of the project will be kept confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. This means that all information will be locked and password protected with access restricted to project personnel.

You will not be asked to provide your name or contact details if you take part in the study so your data (whether completed online or by post) will be anonymous. If you email the research team to ask for information about the study, only the research team will know your contact details and this will be kept on a password-protected memory stick.

Can I withdraw from the study?

You are free to stop responding to the questions and your data will not be submitted *up until you have completed the survey* or *returned the survey in the post*. Once you have finished the survey online or anonymously posted your questionnaires to the research team, your data will be anonymous and it will not be possible to identify and withdraw your data.

What will happen to the results of the project?

This project is intended to form part of a doctoral thesis and we plan to report our findings in scientific journals and also present them to health professionals at meetings, workshops and conferences. This can make people a little apprehensive but we can assure you that the survey is anonymous and individual participants will not be identifiable in any written reports or publications arising from the project. We would like to share the information we learn from this project so that other organisations can better support women who have experienced early miscarriage and stillbirth.

PART 2: What if there is a problem?

Please read the following information where we provide detailed information about who to go to if you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this project.

Who is organising and funding this research? Who has reviewed this project?

The project is being organised and funded by the University of Bath as part of the Doctorate in Clinical Psychology for Kirsty Ryninks. This research has received ethical approval from the University of Bath Psychology Ethics Committee under reference (17-044).

What do I do if I have concerns about the project?

Every care will be taken to ensure your safety during the course of the study. If you have any concerns about the project, please contact a member of the research team below by emailing erlp@bath.ac.uk:

CHIEF INVESTIGATOR – Kirsty Ryninks (Clinical Psychologist in Training, University of Bath)

ACADEMIC SUPERVISORS – Dr Megan Wilkinson-Tough (University of Bath), Dr Antje Horsch (University of Lausanne, Switzerland)

If you wish to complain formally, you can contact Professor Jonathan Knight (Pro-Vice Chancellor for Research) c/o Dr Maria Wells (Executive Officer – Research) by emailing M.Wells@bath.ac.uk or by post to:

Vice-Chancellor's Office, University of Bath, Claverton Down, Bath, BA2 7AY, United Kingdom

Where else can I access support?

If after completing this survey you feel distressed and are worried about your emotional well-being, we recommend that you contact your General Practitioner (GP) to discuss this.

The following list of organisations and publications may be able to provide you with help, both practical and in terms of understanding how you are feeling:

Child Bereavement UK
Child Bereavement UK is the UK's leading organisation that supports families when a baby or child of any age dies or is dying or when a child is facing bereavement.

Website: www.childbereavementuk.org
Helpline: 0800 02 888 40

Sands (Stillbirth and neonatal death charity)
Sands is a national charity that offers support to anyone affected by the death of a baby.

Website: www.sands.org.uk
Helpline: 020 7436 5881

Miscarriage Association
Miscarriage Association is a national organisation that offers support to anyone who has been affected by miscarriage.

Website: www.miscarriageassociation.org.uk
Helpline: 01924 200 799

Birth Trauma Association (BTA)
Birth Trauma Association supports women who have had a traumatic birth experience.

Website: www.birthtraumaassociation.org.uk

Cruse Bereavement Care
Cruse Bereavement Care promotes the wellbeing of bereaved people and supports anyone bereaved by death to understand their grief and cope with loss.

Website: www.cruse.org.uk
Helpline: 0808 808 1677

Care for the Family
Care for the family is a national charity which aims to promote strong family life and to help those who face family difficulties, including bereavement.

Website: careforfamily.org.uk

Samaritans
Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair.

Website: samaritans.org.uk
Helpline: 116 123

Version 2: **07.11.17**

Department of Psychology | UNIVERSITY OF BATH

EMOTIONAL REACTIONS TO LOSS IN PREGNANCY

Demographic Questionnaire

Please answer the following questions about yourself. This is to let us know whether the survey has reached a wide range of different people and to check that you are eligible for the study.

About you

1. How would you describe your gender?

☐ Female ☐ Other

☐ Male

If you selected Other, please specify if you wish (optional)

_____

2. How would you describe your ethnicity? Choose one option that describes your ethic group best.

☐ White British ☐ Black British

☐ Other White background ☐ Other Black

☐ Asian British ☐ Multiple/Mixed Ethnic Groups

☐ Other Asian ☐ Other

If you selected Other, please specify if you wish (optional)

_____

3. How would you describe your marital status?

☐ Single, never married ☐ Divorced or separated

☐ Married/civil partnership or cohabiting ☐ Prefer not to say

4. What is the highest level of schooling you have completed?

☐ No schooling ☐ Degree qualification or above

☐ Left school without qualifications ☐ Prefer not to say

☐ GCSE qualifications or equivalent ☐ Other

☐ A-Level or equivalent

If you selected Other, please specify if you wish (optional)

_____

5. What is your current employment status?

☐ Full-time ☐ Student

☐ Part-time ☐ Homemaker

☐ Prefer not to say ☐ Other

If you selected Other, please specify if you wish (optional)

_____

6. What is your current profession (if applicable)?

_____

_____

7. How old are you?

_____

_____

About your pregnancy

8b) Have you experienced a stillbirth (at 24 weeks of pregnancy or later) or an early miscarriage (before 12 weeks of pregnancy) between 24 months and 6 years ago?

If you have experienced multiple miscarriages or stillbirths in this time, please answer this question in relation to the loss that affected you most. There is no right or wrong choice for this. We ask you to focus on a particular loss to help answer the questions as they are worded. For any other losses in this time period, please outline them in question 9.

☐ Yes, a stillbirth ☐ No

☐ Yes, an early miscarriage

8c) If you answered "Yes" in question 8b), what was the exact date of your stillbirth or early miscarriage?

_____

8d) Approximately how many weeks pregnant were you when you lost this baby?

☐ 1-4 weeks ☐ 28-31 weeks

☐ 5-8 weeks ☐ 32-35 weeks

☐ 9-12 weeks ☐ 36-40 weeks

☐ 24-27 weeks ☐ Over 40 weeks

9. Previous losses

Have you had other miscarriages or stillbirths in the past? If so, when? Please answer this question in relation to any other losses you have experienced, other than the one in question 8b) to 8d) above.

a) Early miscarriage (occurring in the 0-12 week period of your pregnancy)

☐ Yes ☐ No

Dates (year) _____

b) Late miscarriage (occurring in the 13-23 week period of your pregnancy)

☐ Yes ☐ No

Dates (year) _____

c) Stillbirth (occurring at 24 weeks of pregnancy or later)

☐ Yes ☐ No

Dates (year) _____

10. Do you have any living children?

☐ Yes ☐ Prefer not to say

☐ No

If you selected Yes, please specify how old your children are and whether they are children that you gave birth to, adopted, fostered or your step-children.

_____

_____

11. Are you pregnant at the moment?

☐ Yes ☐ No ☐ Prefer not to say

Thank you for answering the questions about yourself and your loss. The next questions will ask you about your emotional wellbeing. Please be as honest as you can and remember that there are no right or wrong answers.

Version 2: **10.10.17**

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EMOTIONAL REACTIONS TO LOSS IN PREGNANCY

Survey Questions

Miscarriage and stillbirth are unique painful experiences and each person will experience different emotional reactions. As time passes, some people will find their emotional reactions more manageable, but for others they can last longer and be very distressing.

Please answer the following questions about your emotional well-being. The questions will ask about different reactions and some may not be something that you have experienced. The questions are from standardised questionnaires that have been tested in different studies – using them means that the results from this project will be more reliable. However, this does mean that the wording may not always seem appropriate. **For all questions that refer to "the event", "the trauma" or "the incident", please think about "losing my baby". If you have experienced multiple losses in the last 24 months to 6 years, please answer the questions in relation to the loss that affected you most. There is no right or wrong choice for this. We ask you to focus on a particular loss to help answer the questions as they are worded.**

Please do not spend very long thinking about any of your answers – read each question and answer it as quickly as possible. Try to be as honest as you can and remember that there are no right or wrong answers.

The PHQ-8, GAD-7, PGS, PCL-5, PTGI, CBI, DTQ and ERRI questionnaires have not been included in this appendix in order to comply with copyright law. Only questionnaires relating to actual self-disclosure and experience of completing the survey have been included.

Talking to Others

If you have experienced multiple losses in the last 24 months to 6 years, please answer the following questions in relation to the loss that affected you most.

1. First month

a) In the first month after losing your baby, how much time did you spend talking to others (e.g. friends, family, healthcare staff or anyone else) about your feelings about losing your baby? (Please give an estimation of the number of hours)

_____

b) In the first month after losing your baby, do you think you talked enough about your feelings about losing your baby?

No, I did not talk enough	Yes, it was about right	No, I talked too much
☐	☐	☐

2. First Year

a) In the first year after losing your baby, how much time did you spend talking to others (e.g. friends, family, healthcare staff or anyone else) about your feelings about losing your baby? (Please give an estimation of the number of hours)

_____

b) In the first year after losing your baby, do you think you talked enough about your feelings about losing your baby?

No, I did not talk enough	Yes, it was about right	No, I talked too much
☐	☐	☐

3. Second Year

a) In the second year after losing your baby, how much time did you spend talking to others (e.g. friends, family, healthcare staff or anyone else) about your feelings about losing your baby? (Please give an estimation of the number of hours)

_____

b) In the second year after losing your baby, do you think you talked enough about your feelings about losing your baby?

No, I did not talk enough	Yes, it was about right	No, I talked too much
☐	☐	☐

Thank you for taking part in this study. We really value your participation. We hope that the outcomes of this project will improve our understanding of emotional reactions following early miscarriage and stillbirth and improve the help and support offered to women and their families in the future.

QUESTIONS ABOUT COMPLETING THE SURVEY

Has your experience of completing these questionnaires at the moment been:

☐ Very positive
☐ Positive
☐ Neither positive or negative
☐ Negative
☐ Very negative
☐ Prefer not to say

Do you believe that completing these questionnaires will be a positive or negative experience for you in the long-term?

☐ Very positive
☐ Positive
☐ Neither positive or negative
☐ Negative
☐ Very negative
☐ Prefer not to say

Do you think that you may contact someone (either your GP or another professional organisation/support group) to speak about your loss as a result of taking part in this research?

☐ Yes
☐ No
☐ Not sure
☐ Prefer not to say

Having completed this survey, I agree to submit my responses and understand that once I have submitted the survey I will be unable to ask for my data to be withdrawn as it will not be possible to identify my anonymous responses. I agree to the research team keeping and processing the data I have provided during the course of this study and archiving and sharing this data with other researchers in the future.

☐ Yes ☐ No

Version 2: **28.07.17**

Department of Psychology | UNIVERSITY OF BATH

EMOTIONAL REACTIONS TO LOSS IN PREGNANCY

Debrief Sheet

Thank you for taking part in this study. We really value your participation and hope that the outcomes of this project will improve our understanding and enable us to improve the help and support offered to women and their families following early miscarriage and stillbirth.

What happens next?

On completion of the project, a summary of the findings will be made available to participants who wish to receive them in the summer of 2018. If you would like to receive this written summary of the findings, please email the research team at erlp@bath.ac.uk to request this.

What do I do if I have concerns about the project?

Every care has been taken to ensure your safety during the course of the study. If you have any concerns about the project or your participation in the research, please contact a member of the research team by emailing erlp@bath.ac.uk If you wish, we can arrange for someone to call you to discuss your concerns within three working days.

Where can I access support?

We recommend that you contact your General Practitioner (GP) if you feel distressed and are worried about your emotional well-being after taking part in this study. If you have found it upsetting to answer questions about your experiences, you may wish to seek some support.

We have prepared a list of resources for participants who have taken part in the project so that you are aware of what options are available if you feel you would like some additional support. Please note that we do not expect you to be looking for support but we wanted to keep this list as comprehensive as possible. The list is not exhaustive however and we cannot specifically recommend each website/organisation or guarantee the quality of each.

The following list of organisations may be able to provide you with help, both practical and in terms of understanding how you are feeling:

Child Bereavement UK

Child Bereavement UK is the UK's leading organisation that supports families when a baby or child of any age dies or is dying or when a child is facing bereavement.

Website: www.childbereavementuk.org
Helpline: 0800 02 888 40

Sands (Stillbirth and neonatal death charity)

Sands is a national charity that offers support to anyone affected by the death of a baby.

Website: www.sands.org.uk
Helpline: 020 7436 5881

Miscarriage Association

Miscarriage Association is a national organisation that offers support to anyone who has been affected by miscarriage.

Website: www.miscarriageassociation.org.uk
Helpline: 01924 200 799

Birth Trauma Association (BTA)

Birth Trauma Association supports women who have had a traumatic birth experience.

Website: www.birthtraumaassociation.org.uk

Cruse Bereavement Care

Cruse Bereavement Care promotes the wellbeing of bereaved people and supports anyone bereaved by death to understand their grief and cope with loss.

Website: www.cruse.org.uk
Helpline: 0808 808 1677

Care for the Family

Care for the family is a national charity which aims to promote strong family life and to help those who face family difficulties, including bereavement.

Website: careforfamily.org.uk

Samaritans

Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair.

Website: samaritans.org.uk
Helpline: 116 123